Approaches and Moral Considerations of a Liver Transplant Team to Conflict About the Treatment of Complications

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Abstract

Research on the approach to disagreement among patients and providers has generally focused on internal medicine providers. High levels of emotional intelligence and empathy among individual internists appear to confer increased adherence to treatment plans and satisfaction among patients. These qualities may help maintain long-term physician-patient relationships. In the few studies examining surgeons, emotional intelligence, but not empathy, results in increased patient satisfaction only. Some therefore suggest that the clearly defined and short-term relationship between surgeon and patient subverts the need to foster deep empathetic understanding and trust for long-term follow-up. Transplant surgery may be a unique surgical sub-specialty for its use of scarce resources, and because patients are followed over the long-term by interdisciplinary teams of providers. I present the results of a qualitative study suggesting transplant teams may function more like internal medicine teams than other surgical sub-specialties, because transplant social workers and nurses foster trust and empathy, reducing conflict among and between team members and patients. I analyzed the narratives of six liver transplant team members at a large academic medical center in the Midwest. I define the sources of conflict perceived by transplant team members, which extend beyond treatment non-adherence, and their underlying moral understandings. I also describe the importance of trust-building, and the role of the transplant team as a moral community, which functions to examine and decide upon conflicts that arise over broad contexts. These results suggest interdisciplinary transplant teams take on some of the emotional work typically performed by individual internal medicine physicians.

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Chapter 1. Background

The purpose of this study was to assess the ways liver transplant teams approach conflict between or among themselves and patients or families when there is disagreement about treatment options for post-surgical complications. It was also to assess the moral considerations the care team takes into account in this context.

1.1 Liver Transplantation in General and Current Literature on Non-Adherence

Transplantable livers are a scarce resource. In 2016 the United Network for Organ Sharing (UNOS) tracked 7,841 liver transplants. Yet as of April 6, 2018, 13,954 patients remained on the liver transplant candidate list (based on Organ Procurement & Transplant Network data accessed online, 4/6/2018). Bioethicists generally recognize that such scarce resources must be rationed according to some justifiable criteria that ensures responsible use; often this includes some aspect of medical utility or "success" (Beauchamp & Childress, 2012; Jonsen, Siegler, & Winslade, 2015). In the transplant context, "success" has been defined in terms of graft and patient survival within one year, which is a reliable surrogate for long term (5-year) survival (Fortune, Martinez-Camacho, Kreidler, Gralla, & Everson, 2015; Kanwal, Duali, Spiegel, Yee, & Granlek, 2005). The Mayo Clinic's publicly available patient information asks patients to expect, "six months to a year of recovery before [feeling] fully healed," and they describe 5-year patient mortality statistics, bounding success between 1 and 5 years (Liver transplant, 2015).

1.2 Treatment non-adherence

Nonadherence to the clinical plan of treatment is common among organ transplant recipients. A review article of "noncompliance" in organ transplant shows that physicians expect patients to take prescribed anti-rejection medications, attend follow-up clinic and lab appointments, modify their diet and exercise, and avoid tobacco and other substances (Laederach-Hoffmann & Bunzel, 2000). The same authors found that on these adherence criteria, overall nonadherence rates vary from 20-50% across studies of organ transplant patients and they describe this as an "incredible waste of financial resources." Responsible use of scarce resources entails efficient use of finances, especially when the organ could potentially go to a less wasteful and more responsible recipient.

Ovid Medline has catalogued 17 studies with the MeSH search terms "liver transplantation" and "treatment refusal" between 1999 and 2009. Many more are listed with the terms "liver transplantation" and "patient non-compliance," however these focus largely on rates of non-adherence. I will focus on the former here because "refusal" implies active consideration of medical options, as opposed to "non-compliant" patients who may be unable to adhere to treatment plans. In 10 of these studies, this has been examined in terms of adherence to antirejection medication regimens and attendance of follow-up clinic and lab appointments *vis-à-vis* Laederach-Hoffman & Bunzel (Berquist, Berquist, Esquivel, Cox, Wayman, & Lit, 2008; Drent, De Geest, & Haagsma, 2006; Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004; Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007; O'Carroll, McGregor, Swanson, Masterton, & Hayes, 2006; Shemesh, 2004; Shemesh et. al., 2004; Shemesh et. al., 2007; Molmenti et. al.,

1999; Venkat, Nick, Wang, & Bucuvalas, 2008). Eight of these 10 studies were conducted in pediatric cohorts. The other 7 reports include one psychiatrist's reflection on a patient who refused to undergo transplantation because the patient feared he would have an alcoholic relapse (Brody, 2009), two epidemiologic studies of alcoholic relapse post-transplant (Lasi et. al., 2003; Pageaux et. al., 2003), one superior court decision of a Jehovah's Witness patient who refused blood post-transplant (In re Duran, 2001), one case-series of patient refusals due to religious reasons (Barnes & Plotnikoff, 2001), and one journalistic report of an adolescent who refused care due to treatment burden after undergoing two failed liver transplants (Gorman, 1994).

Finally, one report documents a panel discussion with a psychiatrist who attended the case of a "difficult" patient with depression and borderline personality disorder. She refused to take antirejection medications after receiving a liver transplant for fulminant liver failure secondary to acetaminophen overdose (Huffman, Popkin, & Stern, 2003). This article is particularly useful because this case occurred at the same facility in which the current study was conducted, and it describes the psychiatrist's perceptions of the transplant team's response to the patient's refusal of care. This patient manipulated the night nurse into allowing her to skip immunosuppressant doses because of nausea. When this was discovered by the day nurse and reported to the attending physician; he came to the bedside and became angry. He yelled at the patient, berating her "generally awful and noncompliant behavior after we saved [her] life." He then yelled at the day nurse and blamed her for the patient's nonadherence, telling her she would be responsible if the liver failed. The day nurse, in turn, called the night nurse at home and yelled at her while within earshot of the rest of the unit. This psychiatrist also states that such post-transplant

conflicts can be avoided with a clear "pre-transplant contract" between the psychiatrist and the patient.

1.3 Pre-transplant contracts

The idea of a pre-transplant contract is problematic in the larger context of surgery. In one instance, when asked to consent to a drain placement that the care team considered to be a relatively simple solution for an abscess that complicated an ileocolic resection, the patient refused "saying that he was unaware that additional procedures might become necessary postoperatively" (Mazotas, McKnelly, Wall, Kodner, & Keune, 2013). The care team wondered whether they should respect the patient's refusal, considering the procedure was of relatively low risk and was in the patient's best interest. They believed the drain placement to be a necessary treatment in the patient's overall operative course, but the patient himself did not. This suggests that the definition of care necessary for a surgical procedure may differ between patients and providers.

Refusal of care may be difficult for surgeons to accept because they are trained according to a "covenantal ethic" defined as "a promise to battle death" on behalf of the patient (Cassell, Buchman, Streat, & Stewart, 2003). Cassell explains that for surgeons, "it is wrong, even immoral to deprive [patients] of that chance [at life]," even when the quality of the saved life is poor. This attitude manifests as what Schwarze et. al. (2010) coined the "surgical buy-in," which Mazotas explains is an "implicit pact that surgeons may believe they make before beginning an operation." In this contract, the patient is presumed to consent, "not only to the operative procedure…but to the postoperative surgical care anticipated by the surgeon" (Schwarze, Bradley, & Brasel, 2010). A pre-

transplant contract may be reasonable according to the psychiatrist in the case discussed above, but it becomes problematic when it is not clearly defined. Schwarze et. al. performed a survey of vascular, neurological, and cardiothoracic surgeons in 2013 and found that 62% of surgeons felt an informal contract about aggressive postoperative treatments was acceptable and 60% would possibly refuse to operate if the patient chose to limit life-saving interventions (Schwarze, Redmann, Alexander, & Brasel, 2013).

It may be reasonable to expect patients to adhere to follow-up appointments and antirejection medication regimens, or include these as part of an implicit contract, since organ rejection and complications in general are obvious consequences of nonadherence. However, the focus of the literature on medication adherence and clinic attendance has limited value. In my clinical ethics experience, the non-medication related complications described above may also be the basis for patient refusal of life-saving interventions in the postoperative period. One study comparing obese to non-obese liver transplant patients showed that the most common cause of death within 6 months was infection (Nair, Cohen, Cohen, Tan, Maley, & Thuluvath, 2001). Another assessing the importance of cardiac events in short-term (<4-months) mortality showed that 90% of deaths were attributable to surgical or medical complications (type not specified), and primary cardiac events occurred in 6.6% of their study cohort. 3.3% of these were intraoperative events (Eleid, Hurst, Vargas, Rakela, Mulligan, & Appleton, 2010). Finally, a 2010 study assessing long-term (>1-year) mortality shows that only 28% of deaths are due to hepatic causes. In that study, mortality was due to malignancy (22%), cardiovascular causes (11%), infection (9%), and renal failure (6%) (Watt, Pedersen, Kremers, Heimbach, & Charlton, 2010).

Other non-medication related complications are common within the first five years. Proxy measurements for complication in the first five postoperative days include use of mechanical ventilation, hemodialysis, vasopressors, and antibiotics (Fazakas, Doros, Smudla, Toth, Nemes, & Kobori, 2011). Boraschi & Donati (2004) and Gad et. al. (2015) have helpfully described longer-term complications. Briefly, complications can occur in nearly every organ system. They can be classified as biliary, neurological, renal, pulmonary, or vascular and include early rejection, pneumonia, gastrointestinal hemorrhage, small-for-size-syndrome, renal insufficiency, bowel obstruction, post-operative collections, infection, and malignancy recurrence (Boraschi & Donati, 2004; Gad et. al., 2015). Such complications are potentially life threatening. For primary liver transplant recipients between 1997 and 2004, survival rate at 1, 3, and 5 years was 83.3%, 73.6%, and 67.4% respectively. For repeat transplant recipients, these rates drop to 68.8%, 55.9%, and 45.9%, respectively (Based on OPTN data as of April 22, 2016). Accordingly, these complications may serve as an unexamined trigger for patient refusal of treatment in the post-operative period.

The overall picture shows a tension between responsible use of a scarce resource and the principle of patient autonomy. Bioethicists have argued that transplantable livers must be used "responsibly," but western clinical ethicists recognize that patient preferences regarding treatment should be given primacy when possible, including the refusal of care (Jonsen, Siegler, & Winslade, 2015). Quantitative characterizations of treatment refusal, such as rates of non-adherence, have been reported, but their scope and utility is limited. Adherence to burdensome medication regimens and follow-up care appointments are important but do not capture many other cases in which conflict may

arise among and between teams and patients. Furthermore, Ovid Medline has catalogued just 15 studies categorized with the MeSH term "qualitative research" in the context of liver transplant. These studies will not be reviewed here, but they concern the lived experience and quality of life of transplant recipients generally. They do not specifically concern treatment refusal and moral considerations. This study begins to fill in the gap by qualitatively describing approaches to treatment refusal for post-transplant complications and the ethical dimensions of the issue.

1.4 Organ allocation and stewardship: theory and practice

Rationing is the practice of deciding how scarce resources should be divided among those who demand them (Munson, 2012, pp. 629). The Seattle selection committee first brought medical resource scarcity, in the context of organ failure, to public attention during the rationing of dialysis machines for end-stage kidney disease. This anonymous group of 7 individuals, who decided which dialysis candidates would ultimately be allowed to access scarce dialysis machines, became a model of how scarce resources might be distributed among needy individuals; yet important ethical problems arose with the Seattle committee(Blagg, 1999). Foremost, the Seattle committee tended to choose primarily white, middle class patients to receive dialysis, demonstrating inequity in the selection process. This likely occurred because the committee consisted of a lawyer, a minister, a banker, a house-wife, a state official, a labor leader, and a surgeon, all of whom were white and middle- to upper-class.

George Annas brought formal discussion of the inequities of dialysis and organ allocation to light in a seminal 1985 paper considering the Seattle selection committee's

evaluation of a sex worker, a wealthy playboy, and a housewife with several children (Annas, 1985). Annas critiqued the committee's selection process as having unclear selection guidelines, forcing committee members to rely on evaluations of social worth based on their own lives: values customarily held by middle-class Americans. This led to inequity in rationing dialysis machines, with those whose socioeconomic status resembled the selection committee disproportionately awarded life-saving medical treatment. He therefore proposed several alternative methods of rationing, including a free-market approach, a lottery approach, and a reliance on the "customary approach" the clinicians had taken up until that point.

In summary, the free-market approach has obvious ethical problems: those who are able to pay will be able to get a transplant, preventing the indigent from accessing the system. The customary approach—which in the United States in 1985 consisted of individual physicians deciding to transplant their patients—was laden with values held by those individual physicians; primarily these were middle-class values, again leading to inequity in accessing transplantable organs. Annas pointed out that by allowing clinicians to decide to transplant based on their own values, institutions were spared from officially recognizing that middle class values were being utilized, since these values were not codified in any official process. Finally, he suggested a lottery approach. Although a lottery may provide equal access, it does not take need and efficient use of the organ into account. Annas finally settled on a combination of approaches, suggesting that initial screening to be listed should be based on medical criteria only, with those criteria reviewed by a panel of physicians, ethicists, and private individuals. Those on the list would essentially proceed by lottery system, given the difficulty of matching individual

patients with histocompatible organs. Interestingly, while Annas argued that the rightest approach reflects equity, efficiency, and respect for life, he also recognized that it is likely impossible to divorce social-worth criteria from any medical criteria, so no system will be perfect.

General ethical theory around organ allocation continued to develop in light of the values codified by US Congress in the National Organ Transplantation Act of 1984, which specifies that organs must be distributed equitably and efficiently (National Organ Transplantation Act). In their text on transplantation ethics, Robert Veatch and Lainie Ross (Veatch & Ross, 2015) reason that these words are codes for maximization of utility and just distribution of resources, which are founded on the bioethical principles of beneficence and justice. In extended discussion, they argue that these principles are difficult to balance against one another because commitment to each principle may lead to conflicting distribution procedures.

In Veatch and Ross's view, if one is committed to beneficence, then one must attempt to calculate the utility of each transplant. Utility may be calculated according to the medical benefit conferred to the individual patient or according to the impact a transplant has on society beyond the individual. Veatch and Ross quickly exclude basing allocation on societal impact, since making calculations about the social impact of a transplant is extraordinarily difficult (285). Different individuals will value outcomes differently. Individual medical benefit may still be a worthwhile consideration because we can predict the effect on survival and quality-of-life to some degree. However, it is still difficult to know which medical outcomes will be the morally useful ones. In

particular, quality-of-life measures are subjective, and providers cannot assume that organ survival or patient survival are necessarily good or desirable states.

Prioritizing just distribution, i.e. fair opportunity to access medical resources, may be preferable, since utilitarian methods of allocation may ignore, or even support, inequitable patterns of distribution by principle (e.g. racial or socioeconomic inequities). Veatch and Ross argue there are three medical factors justice theories consider: present need, urgency, and lifetime need. In present need, a justice theory will ignore prior medical history and give sick people with organ failure a transplant, despite co-morbidities that may reduce utility (e.g. diabetes). Urgency refers to how soon a patient may die without a transplant and can be divided into those expected to decline imminently but currently feel well and those who feel ill but are medically stable. Urgency also considers whether the organ presently available is likely to be the only match in the near future. Finally, lifetime need considers whether lifestyle factors will lead to future need (293-298).

An ethically justified rationing scheme ideally satisfies he biomedical principle of respect for persons. According to Veach and Ross, this can be achieved long as certain criteria known as "prior constraints" are satisfied. Prior constraints are those duties entailed by the first categorical imperative, in this case the second formulation, that the humanity in others be treated as an end but not as a means to an end. Kant asserted that these duties included not intentionally harming others, not lying to others, not stealing, among others. These are termed "prior constraints" in the parlance of organ allocation theory because any allocation formulae must meet these requirements if respect for

persons is accepted as an axiom for just allocation. Two consequences of this commitment were, for example, the dead donor rule and the right to decline transplant.

One aspect of respect for persons is the right to self-determine, which might imply that the voluntary sale of one's own organs and their purchase is acceptable, assuming the agency of the donor is not impaired as a result. However, this is prohibited in the United States because the organ procurement network is public and in a position to exploit potential donors. Directed donation, that is uncompensated donation of an organ to a particular recipient, is considered acceptable, but only to individually named and known persons. This intends to avoid racist or prejudiced donations that are negative in nature (i.e. "this donation is intended for my daughter" as opposed to "this donation is not intended for any Hispanic person"). There is controversy over donation to a hospital since it may circumvent local organ procurement organization procedures that were crafted to maximize efficiency and fairness (298-301). Though they do not explicitly state why, Veatch and Ross recommend a system that prioritizes justice over utility, since this will give the medically worst-off an opportunity for betterment. This preference occurs in the context of discussion on western liberal political philosophy and judeo-christianity, suggesting this preference is rooted in these values (Veatch & Ross, 2015, pp. 284-305).

In practice, organ allocation has proceeded according to a combination approach, as Annas suggested. The National Organ Transplantation Act created the Organ Procurement and Transplantation Network (OPTN), which developed policies in consultation with a task force that The Act also created. OPTN policy dictates that any medical provider may list a patient who meets medical need for an organ transplant and also creates a system for prioritizing on the list (OPTN, 2018). In the context of liver

transplantation, patients are prioritized based on medical need after they are listed, which is reflected in the model of end-stage liver disease (MELD) score. The MELD score (maximum of 40) is calculated based on biochemical laboratory data, including values predictive of death within three months. Therefore, it directly reflects immediate need. There are also certain modifications based on greater or lesser need not reflected in three-month mortality, such as acute decompensation with likely death within one week (also known as 1A status).

Together these basic procedures reflect both justice and utility concerns. All patients with medical need have access to the transplantation list and priority is given to those with greater need. This is a determination that ignores prior medical history, suggesting whether or not patients are responsible for their condition is not morally relevant. However, patient outcomes must also be reported to the OPTN, with particular regard to complications and mortality reflecting a desire to maximize the efficient use of organs. Listing providers also extensively discuss the psychosocial status of potential recipients, and patients with stable social lives informally receive priority for listing by most transplant programs. This adds de facto social worth considerations to the evaluation which circumvent OPTN listing policy.

Substantial debate has occurred regarding whether patients who are causally responsible for their medical situation should also be held morally responsible, affecting the decision to list. This is the case for alcoholic cirrhosis requiring transplantation. Those who advocate against providing livers to patients with alcohol abuse history do so for several reasons. These patients may be blameworthy for causing their liver failure and we should prefer to transplant those who are not blameworthy but equally sick. Or we

may worry that these patients will relapse after receiving a new liver (assuming we choose to transplant after these patients demonstrate sobriety) (Cohen & Martin, 1991). Proponents of transplantation for these patients, however, suggest that it would be impossible to determine the degree of voluntariness in drinking alcohol, if we did we would not know what degree of penalty drinking alcohol would deserve, and we could not be consistent in applying any standard that did exist (Cohen & Martin, 1991).

Veatch and Ross devote a substantial section of their text to this problem, with the authors disagreeing on whether patients with alcoholism should be transplanted (2015, pp. 306-317). They consider how utilitarians and egalitarians would decide the issue differently (306). Utilitarians will focus on the medical impact of the organ (with social impacts excluded for the reasons described above) in absence of the patient's medical history; They do consider whether downgrading patients engaging in risky behavior could disincentivize that behavior, but conclude that downgrading risky behavior is ultimately a slippery slope, since most health conditions are linked to some voluntary behavior. Egalitarian ethicists, however, would say that people are free to do as they wish, and patients deserve access *in spite of* (as opposed to *regardless of*) their health history. But in the egalitarian case, whether the alcoholic has a claim depends on whether one believes the behavior is voluntary, since voluntary action means that individual had a chance to avoid the outcome, and therefore should be prioritized lower than a patient not responsible for their medical condition.

There is debate as to whether alcohol abuse is involuntary for economic, genetic, psychological, or physiological factors, or whether it is voluntary because patients choose to initiate alcohol use (i.e. taking the first drink) (Fingarette, 1981). Veatch (RMV) and

Ross (LFR) disagree on whether drinking alcohol in the context of addiction is voluntary. One author (RMV) thinks that accepting alcoholism as involuntary leads to determinism and makes ethics moot, so we have to assume voluntariness, or at least soft determinism. He argues that "at least some behaviors have at least some voluntary component…" (pp. 309), and dignity and respect for persons demands acknowledging that. Veatch argues that he does not believe alcohol abuse is morally blameworthy: he simply seeks to recognize the role of the individual in bringing about their own. In my view, this may be a distinction without difference.

Ross (LFR) disagrees. First, she argues that determining the degree of causality of the disease of alcoholism on the behavior of "alcohol use," and whether alcohol use is really the proximate cause of a specific instance of liver damage is intrusive and confounded by too many factors. She argues that even if we could make such determinations, physicians should not, since it is not an obligation to the individual patient, and would have to be kept confidential for Hippocratic (an oath of confidentiality), utilitiarian (the outcome will be the same), and deontologic (respect for persons) reasons. She also argues that "a judgment of substantive responsibility depends on more than [causal responsibility]" (pp. 311). To assign responsibility, the agent must also understand alternatives and be able to evaluate them in regards to values. This cannot be assumed in the patient with disordered alcohol use (Veatch & Ross, 2015, pp. 306-311).

Ultimately, the United Network on Organ Sharing (UNOS) considered four options for transplanting patients with alcoholic cirrhosis in 1990. The first two options were rejected by the committee. First, UNOS could ban all alcoholics because they are

responsible for their condition and second they could agree to transplant all alcoholics, even those actively drinking. The first was considered too harsh and likely relied on a judgment of the patient themselves, not simply health outcomes. The second because those actively abusing alcohol are likely not to adhere to treatment regimens, which is a medical reason not to transplant (Veatch & Ross, 2015, pp. 315).

The other two options reflect how listing and allocation actually play out today. The first moderate option was to transplant after the patient demonstrates a period of sobriety, a view which all physicians on the UNOS ethics committee took. This option sees the patient's history of substance initiation and abuse as irrelevant and recognizes that the outcomes are at least as good as other liver patients (a utilitarian view). The second option was that a history of alcoholism would represent a modest negative factor, and was taken by all non-physicians on the community. This reflects the view that there is some voluntary component of alcohol abuse with moral significance, but not enough to ban these patients all together. This option was never formalized in the calculation of MELD scores. In the end the committee had intractable disagreement and agreed to disagree (Veatch & Ross, 2015, pp. 315-317). In part, the current study evaluates how the moderate options unfold in practice.

1.5 Current research on the provider-patient relationship

Little is known about the ways surgeons resolve disagreements with patients. Studies do show that among both internists and surgeons, higher levels of emotional intelligence (the ability to perceive, integrate, and regulate emotions in oneself and others) confers greater trust (Weng et. al., 2008; Weng, Chen, et. al., 2011) and

satisfaction (Weng, Steed, et. al., 2011) in patients. Early work on surgeon communication styles showed that surgeons offered little discussion of psychosocial issues with their patients, and analyses of conversation showed few empathetic utterances, which led to lower patient satisfaction (Levinson & Chaumeton, 1999). Those surgeons who do express empathy indirectly generate greater patient satisfaction via improved patient-perceived health outcomes, but not trust within the surgeon-patient relationship (Weng, Steed, et. al., 2011).

In 2013, Levinson and colleagues provided a helpful systematic review of the surgeon-patient communication literature. Briefly, Levinson et. al. reviewed 21 unique publications and 13 companion reports (i.e. secondary publications about populations previously described). These encompassed quantitative and qualitative reports that examined communication skills or behaviors during observed or recorded interactions between surgeons and patients or their families, and these studies overwhelmingly focused on general, orthopedic, and obstetric/gynecologic surgeons.

In summary, Levinson et. al. found that surgeon-patient interactions tend to focus on biomedical and informed consent issues. That is, the majority of interactions tend to consist of surgeons communicating prognostic and treatment counseling to patients, with patients asking few clarifying questions. Surgeons tend to ask close-ended questions focused on the history of the present illness, which the authors suggest is logical given the need for surgeons to help patients decide on complex treatment options. However, across studies there were missed opportunities for surgeons to assess patient understanding of their medical situation, risks, and uncertainties. In particular, "There appears to be a challenging pattern that patients show a subtle sign of worry, surgeons do

not comment, patients do not fully share their concerns, and it goes on," which suggests deficiencies in demonstrating emotional intelligence and empathy. The authors speculate that time constraints and discomfort may mediate these deficiencies.

Importantly, lack of surgeon empathy has a detrimental impact on the surgeon-patient relationship. When patients do not perceive their surgeon to show interest in them as an individual person, when they do not solicit and answer questions, and when they do not educate the patient about their health condition, the patient is less likely to recommend them to family members or friends (McLafferty et. al., 2006). Interestingly, survey data using validated instruments designed to assess levels of empathy in physicians reveals that the members of the "people-oriented" specialties such as psychiatry, internal medicine, pediatrics, emergency medicine, and family medicine generally have higher levels of empathy for their patients than the "technology-oriented" specialties, which include radiology, neurosurgery, orthopedic surgery, and anesthesiology (Hojat et. al., 2002).

Empathy has been recognized as important to the provider-patient relationship in the medical, nursing, and social work literature, however understandings of the concept vary. Each concept will be addressed individually below. Studies of physicians have defined empathy as "a cognitive attribute that involves an ability to understand the patient's inner experiences and perspective and a capability to communicate this understanding," and its attributes include perspective taking, compassionate care, and standing in the patient's shoes (Hojat et. al., 2002). Physician empathy is related to increased adherence to treatment plans, patient satisfaction, and ability of physicians to diagnose and treat their patients (Neuwirth, 1997). Physicians with better communication

skills (as assessed by objective observers along task-oriented and psychosocial—such as empathetic—communication skills) are 2.16 times more likely to adhere to treatment recommendations (Zolnierek & DiMatteo, 2009).

A study of physicians with high patient satisfaction ratings generated a model of successful communication practices (Figure 1) (Tallman et. al., 2007). Here, patient satisfaction and adherence to medications were correlated to specific communication behaviors that broadly

included keeping the conversation focused on the patient's agenda, drawing out the patient's story, demonstrating understanding of patient's history, showing empathy and caring, providing detailed explanations, and completing the patient's agenda (i.e. directly addressing concerns brought by the patient).

These communication themes have been demonstrated in other contexts. In a qualitative study of HIV-infected patients, patients described stopping anti-retroviral medications for various reasons, including poor provider explanations of the importance and side-effects of their treatment and lack of recognition of the patient as a whole

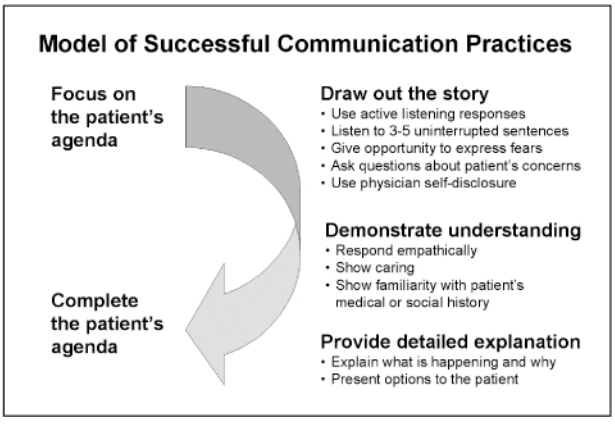

Figure 1. Model of effective physician-patient communication. Adapted from Tallman et. al., 2007.

person. The authors determined that providers must also attend to the patient's experience of illness and attempt to ease its burden. This involves trusting patient description of subjective experience and understanding patient context, both of which contribute to an empathetic relationship (Apollo et. al., 2006). Similarly, among acupuncturists, patients who perceive a greater level of empathy from their practitioner have increased understanding and coping of their illness, and greater self-perceived improvement in symptoms (Price, Mercer, & MacPherson, 2006).

Nurses fulfill a complex set of roles for patients. Their work is advocatory: they question other providers' medical assessments based on their own, attend to medical and emotional needs, give advice, interpret both medical jargon and patient stories, care, connect, and fulfill a "sacred trust" role (Iacono, 2007). Empathy has been recognized as an integral component of the nurse-patient relationship (McCabe, 2004; Reynolds & Scott, 2000) and the social worker-client relationship (Gerdes & Segal, 2011), and there has been interest in empathy as a teachable skill for nursing students (Brunero, Lamont & Coates, 2010). Social work literature suggests that aspects of empathy relevant to the clinical relationship include cognitive, affective, and intentional components. The social worker must identify what another is feeling, experience that feeling, and intend to respond compassionately to distress (Gerdes & Segal, 2011). The cognitive tasks of recognizing the difference between the experience of self and other, and adopting the mental flexibility to temporarily take on the perspective of the other (Decety & Jackson, 2004) are potentially cultivatable.

There is interest in teaching empathy as a skill because of the value that it has in creating a caring relationship between clinician and patient. Nursing literature has

identified a similar skillset, known as "emotional labor." Emotional labor is the difficult and learned skill of modulating one's own emotional states to produce a sense of caring in others (Gray, 2009). Emotional labor is discussed commonly within the nursing literature, perhaps due to the professionalization of the emotional "woman's work." It is a specific type of emotional intelligence that Gray suggests not only enhances the quality of the patient-provider relationship, but also functions to maintain normalcy and smooth institutional function.

Various models of the nurse-patient relationship exist. Recently, Hagerty & Patusky (2003) have proposed a theory of human relatedness (THR) to explain how the nurse-patient dyad forms. They suggest that essential processes to establish a relationship include creating a sense of belonging, demonstrating reciprocity between nurse and patient, demonstrating mutuality (sameness or similarity in some way), and establishing synchrony of nurse and patient activity. They emphasize the role of trust within the nurse-patient relationship as necessary foundations for the above processes. Although the public trusts nurses in general, each individual nurse must establish trust with their patient, since patients are inherently vulnerable in the relationship. Nurses must convince patients of their technical and fiduciary competence, that they have goodwill in general, are open to vulnerability and are vulnerable themselves, and are willing to risk that vulnerability by investing in the nurse-patient dyad (Bell & Duffy, 2009).

Trust has therefore been explored more extensively than empathy in the nursing literature. It is thought to be a major component of the values framework of nursing in general, based on the principles of respect for human value and solidarity with the vulnerable individual (Snellman & Gedda, 2002). Again, social workers have echoed

this, describing the establishment of trust with their clients as instrumental to quickly creating rapport and collaborating with patients (Taylor, 2007). More formally, trust is described as a multifaceted phenomenon comprised of vulnerability (with the implication that something of value can be lost), maintenance of positive expectations about outcomes despite uncertainty, and a belief in the general goodwill between others (Lazzara et. al., 2016). It is generally developed gradually—though may be swiftly established in medical contexts requiring brief interaction—through surface level cues communicated between patient and provider.

Establishing trust consists of several phases, described by Trojan & Yonge (1993): initial trusting, connection, negotiating, and helping. Initial trusting is characterized by a general sense of patient trust by virtue of the nurse as a member of his or her profession who is accepting, respectful, and competent. The connection phase creates intimacy in the nurse-patient dyad as nurses and patients participate in discourse about their daily lives, learn one another's values, and engage in touch during the course of medical and daily cares such as bathing, feeding, and cleaning. The negotiation phase focuses discourse on clarifying client goals and the degree to which the client is willing to cede control to the nurse. Finally, the helping phase sees the nurse fulfill the agenda of the patient as an advocate, educator, care provider, or supporter.

It is important to recognize the commonalities between empathetic and trusting practices described in the nursing and social work literature. In both realms, vulnerability plays a vital role in creating a connection among participants. Empaths must be vulnerable if they are to succeed in utilizing the cognitive skill of mental flexibility, which allows the empath to evoke an emotion in herself. Vulnerability is an essential

ingredient to foster a sense of goodwill between trusting partners. Emotional intelligence is required in both relationships as well. Gerdes & Segal (2011) note that providers must modulate and evoke their emotions while simultaneously recognizing the difference between self and other or they risk becoming overwhelmed by emotion and eventually burnt out. Similarly, a provider must utilize emotional intelligence in a trusting relationship in order to establish the proper degrees of caring, mutuality, and synchrony with their patients.

These considerations are also important to potentially explain why "technology-oriented" medical specialists demonstrate lower levels of empathy than their "people-oriented" counterparts. Both trust and empathy are inherently socially-oriented and typically form over long periods of time. Anesthesiologists, orthopedic surgeons, neurosurgeons, and others are likely able to establish "swift trust" as described by Lazzara et. al (2016), which is a form of trust specific to temporary systems. However, the somewhat well-defined surgical need to remove an infected appendix or gallbladder, replace a broken hip, or stop a brain hemorrhage may not require the same levels of empathy that providers in the "people-oriented" specialties require. In fact, one study of total hip arthroplasty patients found that up to 97% of patient satisfaction scores can be explained by meeting pre-operative expectations, adequate post-operative pain control, the overall hospital experience, and patient reported improvements in symptoms and functioning (Hamilton et. al., 2013).

People-oriented specialties rely largely on preventative medicine or chronic medical treatments that require buy-in to establish adherence and follow-up. Therefore, relatively more literature is focused on the ways internists and general practitioners relate

to their patients. Researchers of primary care and mental health settings believe a strong working alliance—the relationship between patient and provider which focuses on shared goals, task division, empathy, and trust—is essential to fostering a strong long-term patient-provider relationship (Fuertes et. al., 2017). Trust in the physician-patient relationship generally improves adherence, empowerment, patient disclosure, the placebo effect, physician caring behavior (friendliness, empathy, and concern), and both objective and subjective patient outcomes (Lin & Lee, 2009, "Trust but Verify"). High degrees of empathy improve patient satisfaction and adherence, decreases anxiety and distress, improve diagnostics via improved history gathering, improve clinical outcomes, and empower patients (Derksen, Bensing & Lagro-Janssen, 2013).

Fostering a high degree of patient autonomy in the provider-patient relationship may be beneficial for outcomes and the relationship itself by empowering patients to take on responsibility for their care (Lee & Lin, 2009, Trust but Verify). Patient empowerment, which Nafardi and colleagues (2017) define as "patients' perceptions of their own capacity for disease management and their beliefs about how much control they have over their own health outcomes," leads to improved disease management, more efficient utilization of services, improved health outcomes, and medication adherence. In fact, high degrees of patient-physician partnership and perceived empathy may have just as much of an effect on adherence and satisfaction as perceived physician expertise in disease management (Kim, Kaplowitz & Johnston, 2004).

These cultural attitudes have been put into practice in a variety of primary care settings. In studies of, asthma (Bukstein, 2016; Young et. al., 2017), hypertension (Plinski et. al., 2014), diabetes (Lee & Lin, 2009, Effects of Trust), and HIV-infected

patients (Altice, Mostashari, & Friedland, 2001; Graham et. al., 2010; Flickinger et. al., 2016), greater degrees of trust and empathy have been shown to increase adherence to medications and improve both subjective and objective outcomes. Asthma, hypertension, diabetes, and HIV care—like transplantation—all require long-term adherence to potentially complicated medication regimens that may have burdensome side effects. The primary care literature therefore suggests that transplantation teams will experience lower degrees of non-adherence, better long-term outcomes, and more efficient resource utilization if they are able to foster high degrees of empathy and trust with their patients. This study aims to examine this hypothesis, and the findings below will suggest that transplantation teams indeed manage conflict by fostering high degrees of empathy and trust due to their reliance on nurses and social workers as purveyors of care.

Importantly, the reviews cited above do not address transplantation teams. Systematic searches of the MEDLINE and Web of Science databases in fact revealed no empiric literature on empathy or trust within the transplant team-patient relationship. Just one report identified consisted of commentary by bioethicists who suggest that patients who lose several organs due to non-compliance with antirejection medications should be shown empathy and compassion when considering whether to list for re-transplant (Seiden et. al., 1999). This study therefore represents a provisional attempt to describe how transplant teams foster empathy and trust with patients, and who is responsible for such activities.

Chapter 2. Method

2.1 Overview

This study used narrative inquiry to generate themes regarding the ways liver transplant teams approach conflict among themselves or with patients or their families. Narrative inquiry was first described as a qualitative method in the social sciences by Donald E. Polkinghorne (1988). Generally, unstructured interviewing solicits narratives of specific incidents of the phenomenon in question. Close examination of transcriptions generates themes through inductive content analysis within interviews and comparative analysis between interviews. In this study, knowledgeable participants were asked the grand tour question, "Can you give me an example of a time when the patient's course in a liver transplant didn't meet your expectations of how you hoped it would go?" The intent was to elicit stories of conflicts between the care team and patient or their family, but interviews were respondent driven so as to allow interviewees to create meaning in these events without introducing researcher bias. The method was pragmatic in nature, meaning the grand tour question was altered based on themes that emerged during data collection (e.g. "Can you give me an example of a time when your team disagreed with a patient or their family about the treatment plan after the transplant was completed?").

2.2 Participants and Recruitment

I used a purposeful sampling strategy to recruit members of liver transplant teams with knowledge of patient-provider conflict in the liver transplant context. Therefore, participants included liver transplant surgeons, advance practice nurses, registered nurse

care coordinators, and social workers, who identified as members of the liver transplant service. Participants were recruited from a tertiary care facility in the upper Midwest that is a liver transplant center. Because of my experience on the clinical ethics service at the participating medical center, I expected the liver transplant team to be familiar with the phenomenon in question. I have encountered multiple disagreements between patients and the liver transplant team necessitating formal ethics consultation. I aimed for 6-12 interviews with a variety of members of the care team, a sample size known to generate sufficiently rich data to generate themes.

Potential participants self-identified in response to a recruitment letter, or they were approached directly after being identified in consultation with a knowledgeable informant. The inclusion criteria were: 1) participant is a self-identified member of the liver transplant service and 2) the participant is over age 18. Participants were excluded if they did not speak English.

2.3 Procedure

Participants were sent a recruitment letter, recruitment e-mail, and follow-up direct visit to answer any questions. If they agreed to participation, I scheduled a 1-2-hour interview in a location of their choice. I obtained written informed consent from each participant. The participant then completed a short demographic form outlining the participant's professional experience within their professional field and transplantation medicine, in specific. The interview then proceeded and lasted until the participant became fatigued, had nothing more to add to the conversation, or had to end the interview due to professional obligations. The interview was recorded using the Record app for

iPad2 and uploaded to google drive immediately following the interview. All interviews were kept on the researcher's password protected computer or a separate encrypted external hard drive. Interviews were transcribed by a professional transcription service and transcripts were stored on a password-protected computer.

2.4 Researcher Bias

As a method falling under a constructivist paradigm, narrative inquiry is necessarily subject to the interpretation of both researchers and participants. This is not inherently problematic. To make these interpretations explicit, however, the investigator kept reflexive memos during the research project that described issues related to methods, analysis, and personal bias. The investigator also discussed both interview technique and initial impressions with a knowledgeable mentor after each interview.

2.5 Analysis

I used both paradigmatic and narrative inquiry as described in Donald Polkinghorne's "Narrative configuration in qualitative analysis" (1995), which is based on Brunner's descriptions of the two types of cognition (Brunner, 1986). Both types start with descriptions of events and analyze plot to understand the narrative meaning behind them. They produce different yet related results. Paradigmatic inductive analysis uses the content of stories to identify conceptual themes within and among plots through systematic coding, while narrative analysis produces descriptions of specific instances of events. Both types of inquiry were useful here because the literature lacks accounts of both storied conflicts between transplant care teams and patients as well as conceptual approaches to the ethical challenges which arise in these conflicts. I requested the

assistance of expert narrative researchers (Drs. Joan Liaschenko and Cynthia Peden-McAlpine) during my analysis. This provided quality control and external review for bias.

Study transcripts were uploaded to the Dedoose suite, a qualitative and mixed-methods research software. The software suite is encrypted and password protected, and allows users to code and analyze transcripts. Transcripts were then coded for concepts and themes by two independent reviewers (Scheiner and Liaschenko), and disagreements in coding were resolved by discussion and consensus. Codes were assessed for overarching themes before a theory was generated.

2.6 Study Reliability

Lincoln & Guba (1985) have described general validity criteria for qualitative research studies. Their criteria fall into four general categories, including issues of: credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity). They additionally describe reflexivity, which has been addressed above in this proposal. I will not describe all of Lincoln and Guba's criteria here, but special attention should be paid to transferability in narrative studies. Lincoln and Guba define "thick description" as description of sufficient detail such that the conclusions of the study can be transferred to other times, places, and people (1985). Thick description was achieved by interviewing participants for a sufficient amount of time and with high quality unstructured technique.

Polkinghorne points out that the goal of narrative inquiry is to produce truth in meaning, not truth in history (2007). This is to say that narrative researchers need not

necessarily strive for a mirror reflection of participants' experiences in their retellings of those experiences. Instead, Jason Loh adds the criteria of verisimilitude and utility to Lincoln & Guba's validity criteria (2013). Verisimilitude refers to the ability of the description to "ring true" with the reader, or allow the reader to vicariously experience what the narrator has experienced. Utility refers to the usefulness of the study to the wider community. Verisimilitude and utility were the main goals of this study. Meeting these criteria will address a descriptive gap in the literature regarding this moral issue.

2.7 Ethical Considerations

All participants were assigned a pseudonym to protect their privacy. Study records were kept on an encrypted hard drive or locked file cabinet in a locked office. Written informed consent was obtained from all participants. The University of Minnesota Institutional Review Board reviewed and approved this study.

Chapter 3. Results

The major findings of this study are broken into three areas: sources of conflict perceived by transplantation team members and underlying moral considerations, the function of the transplantation team as a moral community, and the trust- and relationship-building practices that teams use to manage disagreement, preceded by a short description of participant demographics.

3.1 Participant Demographics

Six participants, one male and five females, agreed to unstructured qualitative interviews. The participants included one transplant surgeon, one inpatient nurse practitioner, three care coordinators (one registered nurse and two social workers), and one clinical social workers. All participants had significant experience within their discipline (range: 8-34 years) and within transplant medicine. Their professional and personal characteristics are described in table 1. All participants were given pseudonyms.

Table 1. Study Participant Characteristics

Name	**Age**	**Credentials**	**Role**	**Years of Experience in Profession**	**Years of Experience in Transplant**
Dr. Adams	48	MD	Transplant surgeon	27	15

Christine	43	NP	Inpatient nurse practitioner, mainly pre-transplant	8	5
Carol	54	RN	Post-transplant care coordinator	31	15
Susan	45	MSW	Living liver donor coordinator and advocate	12	3
Stacy	60	MSW	Clinical social worker	34	29
Rebecca	35	MSW	Pre- and post-transplant coordinator	13	5

3.2 Findings

In the first section, sources of conflict, the main findings included a perception of behavioral issues as causes of disagreement, including alcohol use, adherence to treatment, and mental health. These conflicts are further examined in light of their underlying moral understandings, including responsibility assignments based on age and perceived voluntariness of non-adherence. In the second section, I describe the role of the transplantation team as a moral community that uses reflective discussion among and between transplantation team members and patients as a way of building consensus on

morally questionable acts. Finally, in the third section I discuss how trust- and relationship-building allow transplantation team members to maintain relationships with patients who do not adhere to treatment plans and to bring their own concerns to the team without judgment.

3.3 Sources of Disagreement

The sources of disagreement between and among the transplant team and patients are broadly conceived of as behavioral (as opposed to non-behavioral issues like infection, rejection, etc.). Social worker Stacy broadly described behavioral issues as "alcohol and drug use, medical nonadherence—be it with their medication, labs, or whatever…" Sources of disagreement include alcohol abuse, treatment non-adherence, and mental health complications.

3.3.1 Alcohol

Substance-abuse was almost exclusively conceived of as alcohol-related, a relevant concern given the relationship of alcohol abuse to liver disease. Alcohol use can cause disagreement before, during, or after transplantation. Christine, NP pointed out the importance of educating patients about the potential impact of their alcohol use before transplant, saying:

> I try not to be too blunt, but sometimes you have to be straight forward and say, 'Our liver team here in the hospital will not transplant you, because…you need…continued sobriety post-transplant.' Everybody uses this less than six-month rule…It isn't just you met the six months rule, and we can transplant you. It's showing that you will be sober and able to take care of this gift.

Here, she introduces the "six month" rule, which requires that patients abstain from alcohol and complete chemical dependency treatment for at least six months before the team will consider transplanting them. She implies that this rule exists for organ stewardship reasons when she refers to the liver as a "gift." Carol, RN and post-transplant coordinator clarified the moral reason for this:

> R: ...It could cause it to fail, it could cause more scarring, it could kill them. And if we think you're going to damage your liver, we don't want to give you a transplant.
>
> I: Why?
>
> R: Because it's a limited resource. We have about 20% to 30% of our people on the list every year that die because they just didn't get one.

Primarily, transplantable livers are recognized as a scarce resource, with many patients dying while they remain on the waitlist. The transplant team impresses upon the patient a moral obligation to abstain from alcohol; not to do so connects the death of another patient to what is perceived to be the liver recipient's selfish acts. Secondarily, the team recognizes the obligation of medical providers not to put patients in harm's way. Transplanting a patient with active alcohol abuse could present health risks due to both the stress of surgery and the complications of inadequate follow-up or direct damage to the transplanted liver.

Participants also acknowledged that the six-month rule is an arbitrary timeframe that is not based on any data which shows this to be a threshold for sustained alcoholic remission. The importance of the sobriety rule can occasionally create inappropriate expectations for transplantation, such as when Stacy, MSW, had to clarify that sobriety does not necessarily imply appropriateness for transplant:

> R: There is a family that I met last fall. The patient was sick, inpatient, and one of the first things the spouse said to me was, 'So what's magic about six months?' Of course, I said, 'Nothing. It's essentially industry standard, and what we do know that is the longer people can maintain their sobriety for any reason, the longer they are projected to have that happen. It's just statistics. It's not magic…' We proceeded from there, and there were other medical issues that needed to be resolved… Six months has passed. The other medical issues have been addressed. The chemical dependency assessment was done…I was talking to a family member, a sibling that was helping set up the needed appointments for follow up substance abuse, care, therapy, etc. She told me, 'I think we all thought that once she hit the six months, listing was automatic.'

Alcoholic relapse was frequently cited as a cause of post-transplant conflict. First, it is a disqualifying factor for re-transplantation, a scenario discussed by Christine, NP who expressed concern about those with alcohol abuse disorder who lack insight into their disease when she said, "I think those patients are the ones that are worrisome for, again, if you transplant them again, they will relapse again." Team members frequently described the difficulties of confronting patients about their alcohol use. Stacy, MSW and Christine, NP both said that patients who have relapsed will frequently minimize the importance of managing alcohol use in conversations or deflect the conversation altogether. NP Christine captured the nuance involved in these discussions:

> R: Part of their fear is of dying, so their coping is drinking. It's this vicious cycle. You try and talk with them about that fear, but it's bad coping, so they deflect. It's sometimes very difficult to have a straightforward conversation, because it just spirals.
>
> I: Spirals into what?
>
> R: Deflecting to something…especially when you are in a situation where they can't hide. I think they feel a little cornered…They say, 'I don't want to die.' These are what you say, 'This is what's going on, you will die, because of where your numbers are.' They say, 'Oh I don't want to…' There's always this deferring to later. I think that happens quite often, looking away, just constantly shutting yourself off…"

In managing these difficult conversations, NP Christine pointed out that she impresses upon the patient a sense of needing to discuss alcohol use "now." However, this does not arise solely from concerns that the organ will be damaged by continued alcohol use.

The technique of employing immediacy to the conversation is for practical reasons: patients may become encephalopathic and then be unable to participate in decision-making, both about alcohol cessation and other treatment options related to transplantation. NP Chrstine generally described the problem this way:

> R: …Some decisions have to be made at certain times. Not that you are like, 'You are going to do what I want only, and we are going to do this now.' You try and bend to what you can, but some patients will defer always. Maybe there is a window where they are clear in their thinking, and you have to take that window, because you don't know what tomorrow will be.
>
> I: Clear in their thinking as in…?
>
> R: Mentation and are able to make decisions. What if tomorrow they are ill and need to get intubated? Well, we could have had that conversation the day before.

Rebecca, MSW, pointed out that in addition to diminishing a patient's ability to receive and communicate information with providers, encephalopathy can distort the process of evaluating that information according to one's values. Here, she described a patient whose mother acted as his surrogate decision maker during his hepatic encephalopathy:

> R: I just think he wasn't necessarily thinking real clearly, which really impacted his emotion about the moment and his ability to process the situation. His mom had to be his substitute decision maker at different times…He usually would still recognize me, and I felt like we still could do some good work…unfortunately he would go from ICU up to [the floor], or down to ICU. He was just switching rooms so often that he wouldn't get a good base of familiar people in his life.

One technique to manage the uncertainty of encephalopathy and surrogacy, however, is to act as an anchor for patients as they fluctuate in cognitive and

decision-making capacity. Rebecca stated she felt she could still do "good work" with the patient because she would see him every day and remind him of his situation.

The team also recognized that remaining sober after receiving a transplant is difficult. One one hand, participants noted the responsibility of the transplant team to assist the patient in maintaining sobriety. However, both physical and social constraints may prevent patients from receiving adequately intensive therapy. Stacy, MSW described the extent to which one patient was asked to participate in chemical dependency treatment and the associated constraints:

> R: This person's recommendations actually were three-fold and many of them were difficult to do. One, was to attend [Alcoholics Anonymous] weekly, and have a same-gender sponsor. One, was to attend…two weeks of intensive education and reflection about substance use…The [third] one was to seek individual counseling. There were several things that needed to be initiated, and health-wise he really couldn't do all of the above. Again, we kind of negotiate what is doable and what can be started now. The program that was recommended doesn't have an opening until May, so that is problematic. Plus, with other health care needs, the person's schedule is not—he also needs dialysis.

On the other hand, participants also conceive of alcoholic relapse as a patient's decision. MSW Stacy, RN Carol, and NP Christine all describe patients who "choose to drink," after receiving their transplant. Stacy detailed one conversation she had with a patient who had relapsed:

> I: When you are sitting in that room and you are having that conversation and he says 'I don't think I really need treatment or I don't see why I need treatment,' what is your response to that? How do you convince?
>
> R: Well I try to convince, but essentially my response is, 'You're right. It's your choice. What you do or not, this is what you and your family had agreed to doing after your transplant. We will continue to take care of you as long as you know these are the potential consequences.' He said, 'fine.'

Carol described how she instills responsibility for alcohol use into the patient:

> R: I'll remind him that a donor's family went through making a choice to donate organs. I feel like there's some responsibility to the donor family, to the people who've cared for them, including their family and their caregivers, and they'll agree, but some people just can't do it. So sometimes they fail.

Team members' tendency to view alcoholic relapse as the patient's decision and to hold the patient accountable to the donor may represent an attempt to delineate responsibilities. On one hand, the team recognizes their role in providing resources to the patient who has agreed to sobriety, but they use the language of choice and responsibility for the patient, because they recognize the active role the patient plays in maintaining sobriety. This also cognitively distances the team from having to accept responsibility for the patient's failure to remain sober, and potentially to protect themselves from responsibility should transplant failure occur. This is not an attempt to shirk responsibility, but a recognition of the active role the patient plays in maintaining sobriety.

As Carol, RN, also pointed out, "[alcoholic relapse] can be really hard on the team" and its relation to other medical providers, as opposed to the relationship between team and patient:

> R: [Patients] end up in a hospital…where the team is like, 'Well, do you know he's drinking?'…Even in our own ICUs, our own nurses, our own physicians, say, 'Why did you give him a liver when he was drinking?' But when it becomes a life and death decision on a young person ... And that's a point of conflict between team members sometimes.

She notes that patients who relapse reduce the credibility of the transplant team by reducing their perception as experts in selecting appropriate patients for transplant.

Carol said that she approaches this conflict with other medical providers by highlighting the unique challenges that working with patients who have alcohol abuse disorders represents. It is only through experience with these patients that she can know how difficult it may be to predict whether a patient will relapse or not:

> R: You try to educate them, you try to tell them that, really, overall, what I've learned in all the years of doing this is that we don't have a good way of predicting who's going to be able to stay clean, dry. You can make assumptions about people, their support systems. Sometimes the people that you think are going to the worst do the absolute best; sometimes the people that you think are going to do great, fail. When you're faced with that life and death option for people when they're young and otherwise healthy, I think we try to give them the benefit of the doubt.

Liver transplantation requires specialized knowledge to understand—in this case, the knowledge that alcoholic relapse cannot be predicted.

3.3.2 Treatment Non-Adherence

As described in the existing literature, treatment not-adherence is a frequent source of disagreement between the transplant team and patients, and within the team. Carol, RN and post-transplant care coordinator, is in a unique position to witness the difficulties caused by treatment non-adherence. She began by describing the story of a young man who received multiple liver transplants:

> R: I have another kid who I transplanted as a baby, took care of him in the hospital, his mom was there all the time. He grew up, stopped taking his medications…He must have been 20. He's now had three transplants, and two of them he lost probably because of noncompliance, and that's hard on the team. Because the team, there are different members that feel different ways…
>
> I: Is there anyone on the team who disagreed with that 'let's give him a second chance; let's give him a third chance'?

> R: Yeah, there's always -- there's a lot of disagreement…Sometimes I'm the one who disagrees…It can be different surgeons, it can be different social workers…

As I will discuss below, these disagreements are eventually resolved by team deliberation and consensus.

Importantly, most treatment non-adherence is perceived in the context of adolescents and young adults. Multiple participants explicitly referenced these populations when prompted to discuss non-adherence. Carol, RN described a desire to "be normal" as the likely reason why young people stop attending clinic or taking medications:

> R ...it's hard to get a transplant, because…when they get better, they go to school, and they start to realize that they're maybe not as normal as other kids. They have to take pills that other kids don't have to. In liver transplant, you don't see a lot of side effects that make people look different. Kidney transplants you do, so maybe they get hair growth. Maybe they get chubby faces. They just don't want to be sick any more. So they'll just push it aside and maybe run away for a while or rebel.

Carol went on to describe the extent to which non-adherence because of mental illness and inadequate social support—which are often co-morbid—affects treatment. She described one young man with bipolar disorder who abruptly moved from the Midwest to the west coast in order to write a movie, another who, with inadequate parental support, ended up in jail and stopped taking his anti-rejection medications, and a third patient who attempted suicide.

3.3.3 Mental illness

Carol's story of Andy, the young man who moved to California, revealed how disruptive decompensations in mental health are to the continuity of care for transplant recipients:

> R: Andy is another alcohol chemical/dependency-type patient…And he had a lot of mental health issues. He did have a mom who lives in California, so he didn't have a lot of support here. He had a friend who was supposedly his support, kind of had a home, kind of didn't, kind of lived with different people, and he was young and healthy, and we transplanted him, and he was on, like I said, three psychoactive-type medications.
>
> I: For what condition?
>
> R: …Maybe bipolar disorder. So they need mental health follow-up, and getting him to go was just, sometimes ... He didn't even have a car at the time. He didn't actually have a home by the time he got out of the hospital from his transplant. He, too, disappeared on me for a while...he took off and went to California because he's a film writer. He's making a movie about a surfer, and he's like, 'Oh, well, I'm going to go for about six months, Carol. You're not going to make me not go. This is my life.' I'm like, 'Okay. While you're there, at least please get some labs.' ... 'Oh, yeah, yeah, yeah. I will, I will, I promise.' Then he disappeared. Then he came back.
>
> I: When Andy went…did he do what he needed to do?
>
> R: No. Oh, he did with his work, but he totally disregarded his health and his medications. You can never know for sure. I think he probably took them some of the time.

This patient, who may have been experiencing mania following his transplantation, did not adhere to two of the most basic requirements of transplant follow-up: taking antirejection medication and attending follow-up clinic and lab appointments. For Andy, mania likely changed his perceptions of risks and consequences, reducing his ability to foresee the consequences of stopping his anti-rejection medications. Instead he may have

become mainly focused on the grand idea of writing and producing a movie within 6 months.

The assignment of responsibility is also important in discussions of mental health. In describing a patient who attempted suicide by stopping his anti-rejection medications, Carol, RN said:

> R: We tell everybody they need to have a primary care doctor. We do our best to remind them, if they have any history of depression, to see a mental health provider. So we take it on, but you can't make people walk where you want them to walk. You take it on, you mention it to them, you talk to them about it – and he was like a star patient, so he was the last one you would expect to have something like that. You know, we asked him about it, we talked to him about it, and they can choose to tell or not tell. And they get sick of telling, sometimes. So I think it's maybe just, some people do the best they can do, and then they don't.

Here, as in the case of alcohol abuse, patients with depression are encouraged to see appropriate care providers and given resources to do so. However, patients are given ultimate responsibility for whether they manage their own mental illness.

Finally, completed suicide was particularly difficult for the team to process. Rather than a cause of overt disagreement between parties, suicide prompts internal conflict among participants and within the group as a unit. Carol provided an example of a time when a patient completed suicide after he discovered he had recurrent cancer:

> R: …Our response was horrified…We develop really strong relationships with these patients. We try to remind them that we have resources for them, we're available to them; and you feel kind of defeated…As a nurse, you're very in touch with people's feelings, and empathize, and try to put yourself into their place, where they've already troubled their family with all that it takes to get a transplant, the cost of the transplant -- and then they see another big cancer diagnosis and more treatment down the line, and you can try to understand that they just couldn't do it any more…I guess initially there's sometimes a little anger there, because you've given your whole...I mean, the whole team dedicates a lot to these patients, and then you feel sadness for the family and you feel sadness for the patient. I think the anger

> part for me was really quick, because you're like, 'Gosh, he had a perfectly working liver.' So that's hard to take sometimes.

Here, Carol illustrates how the team struggles to reconcile the effort and resources they have put into this particular patient, particularly in light of their role as stewards of a scarce resource.

3.4 Non-behavioral issues

Participants described various non-behavioral treatment complications which were relevant to clinical decision-making, but were not sources of disagreement (in contrast to behavioral-issues described above). These ranged from acute or chronic rejection, to infections caused by biliary duct leak, to malignancies which were commonly attributed to immune suppression medications. Participants were specifically asked whether patients ever refuse to have treatment for medical complications following transplantation, and whether this causes disagreement among or between the team and patients. Participants were unable to identify any such scenario. Interestingly, patients are expected to request treatment for these complications as they are seen as a "routine" part of post-transplant care. They therefore do not represent sources of disagreement between the transplant team and patients. This was illustrated by Rebecca, MSW, as she described the treatment of a patient with primary liver non-function:

> R: …when anyone has what they call primary non-function, I think they were deemed to be a good candidate for a transplant. It's not their fault that the first one didn't work and it's not necessarily the surgeon's. It just didn't work. They have a very reasonable chance of doing well with a second one if they can get it within that window of opportunity, because if you have a non-working liver, you're not going to live very long—days…We re-transplant that patient if they're medically stable enough…I don't actually think it becomes a big ethical dilemma in the moment, because the first one

> didn't work. If the patient is stable enough …I don't think that's a hard decision at all for the surgeons.
>
> I: Because they're not thinking about the liver?
>
> R: There's not maybe a good reason to think that second transplant's going to do the same thing—not work. I actually have never seen that. We've only had a few cases where someone's had to be re-transplanted within a couple of days because the first one didn't work. It doesn't happen very often, luckily.

The certainty with which NP Christine stated this patient would be re-listed and re-transplanted draws out the fact that sometimes a patient is not assigned responsibility for their complications at all. In this case, loss of liver function cannot be attributed to the patient's misbehavior, as the patient did not have the liver long enough to take any harmful action. Nor is the transplant physician held responsible in such a case. The liver was lost entirely due to a physiologic process outside the control of the patient. Non-behavioral complications therefore do not represent sources of disagreement between the team and the patient.

3.5 Moral Considerations that Underlie Conflict

3.5.1 Organ Stewardship

The most ubiquitous underlying moral commitment of the team is to the role of responsible organ stewardship. Responsible organ stewardship refers to the equitable distribution of scarce transplantable organs based on ethically sound criteria. All participants described discussing the need for proper distribution of livers either in the context of pre-transplant selection evaluation or directly with recipients and families.

Clinical social worker Rebecca immediately described a sick patient, Eve, and appropriate use when asked what considerations the team makes when selecting a patient:

> R: Well, we meet as a team every Tuesday in our conference section…There were constant infections and things like that, so what we're really looking for in those moments is do we have a window of opportunity, and her course was just really tough, and she was getting so de-conditioned, and there were just many reasons why it wouldn't have been unreasonable to say no, it's not a good idea to proceed. I think the push from the family begging—please try this—and that's not uncommon that family members want us to try to do it even if the percent chance is ten percent that they would survive. Well, ethically, we have to have a better percentage than that in order to proceed. We don't usually put percentages on a situation, but when there's a lot working against a patient, there has to be…they're really looking at can she make it through this? Is this a good use of resources when we're a team that's supposed to make those kinds of decisions about there being a shortage of resources? She was high-risk.

Rebecca later told me, "a donated organ is very precious. We don't have extra ones just sitting on the shelf," explicitly confirming that scarcity of livers—that if this patient receives a liver, another patient will be unable to receive one—is the primary consideration in deciding to list.

Stewardship considerations are not limited to discussions within the transplant team. Several participants said that they would explicitly tell patients that the organ must be used responsibly or to its maximal capacity. Dr. Adams, for example said, "There are patients I tell 'You are not going to survive a transplant. You should not have a transplant,' because, honestly, they wouldn't do well." In part he meant that he wished to see a successful medical outcome for a patient, but in light of the above discussion, he can also be taken to mean he would not wish to give a scarce liver to a patient who would not put it to "good" use.

In another instance, clinical social worker Stacy described a conversation she had with an alcoholic patient: "...He is very well aware that if his liver were to fail and he continues to drink, he said, 'I know that I wouldn't qualify for another one.'" Alcohol abuse presents a particularly difficult complication in stewardship deliberations. On one hand, participants recognize that patients can attain and maintain sobriety, and therefore can receive a liver and use it "responsibly." On the other, if a patient with a history of alcohol abuse relapses and their liver fails, then the team has made an improper liver allocation and the patient will be disqualified from receiving a second.

The team's commitment to stewardship even penetrates the clinical decision-making process after a patient has received a transplant. Stewardship makes certain treatments objectively ethical, meaning they do not depend on the patient's or providers' other values to take on moral correctness. Instead of considering whether a complication should be treated in light of the patient's values and potential quality of life, the patient should be treated because the liver must be protected. Clinical social worker Rebecca described this, saying:

> R: …When the surgeons meet with the patients early on in the discussion about transplant, they explain pretty thoroughly of the risks of complications that they're very high, and people often get brought back to the OR for additional needs and things like that. They kind of normalize that actually... They're always trying to save a donated organ, no matter whether if it's from a live donor or a deceased donor.

Stewardship conversations can also be a source of conflict between the team and the patient or their family. Such explicit conversations about a liver, an inanimate object, can create frustrations about the welfare of the patient. Social worker Rebecca discussed the

case of a patient who was denied listing for a second transplant because he had medically decompensated and likely would not survive long after the procedure:

> I: What was the family's response when you told them we can't offer this?
>
> R: …The daughter was the next of kin and his healthcare agent. She was angry. She was angry and at the same time respected our decision. She was angry because she had worked really hard, and she really had, to help him get to the point of hopefully having a transplant. She would come with him to all his appointments; she really was very involved. I think in her mind, if she could help her dad get to this, it would happen and then it wasn't going to happen. So not necessarily angered toward us, but angered at the situation, and she obviously wanted a different outcome.
>
> I: What did you say to her when she expressed that anger?
>
> R: Just reflecting that I understand why you're angry, I feel for you in this situation, this is a very difficult situation for us to be in as well as for you. This is your dad; he's not going to make it. She was very tearful. A lot of our patients get really frustrated about the allocation system and the MELD [model for end-stage liver disease] scores. You had to have a high enough MELD score to get here, and now it is high, and now you can't transplant on him. So again, more anger directed at the system that is created to allocate organs and how it's not fair. That actually happens quite a bit on the pre-side for us. So validating her feelings, because many of her thoughts and frustrations are not unfounded; it isn't always a fair system, and it is difficult.

UNOS selection criteria mandate that patients have a certain level of liver failure, measured by a score system called the "model for end-stage liver disease" or "MELD." Unfortunately, liver failure makes major surgery riskier, and as such there is a fine balance between appropriateness for transplantation from a stewardship perspective and from a technical perspective. These act as opposite sides of a balance: if a patient is not sick enough, the principle of stewardship demands they not be transplanted. If a patient is too sick and may have a poor surgical outcome, the principle of stewardship also demands they not be transplanted.

3.5.2 Who is responsible for "bad" behavior?

Examining the ages of patients involved in stories of complication revealed that notions of moral responsibility differ whether the patient was an adult or a child. Christine, inpatient nurse practitioner put the issue most poignantly when speaking of a child who was non-compliant with medications saying:

> R:…you want to give them a second chance, usually it's the kids. Kids make stupid decisions. Shocker, right?...So, you give them that chance. If it happens again, then we are in that same boat as someone who is noncompliant. Just like someone who had been drinking, you gave them that chance and now they are right back…

Here, she captures several important moral understandings of three patient populations at once: children and adolescents in general, adults in general, and patients with chemical addiction.

First, in considering adult versus adolescent decision-making processes, NP Christine draws a distinction in the moral responsibility of patients who are non-adherent based on age. She went on to describe the difference between adults and adolescents:

> R: …This is something that our transplant selection group struggles with, because they are young. Someone who maybe made some poor decisions as a teenager, because they are struggling with separating from mom and really not able to make, I hate to say, adult decisions. Really, they are not mature enough yet to be able to understand what the decisions that they make right now as they are separating from mom and dad, how that effects [them] long term versus someone who is adult should be able to understand immediate acts and long-term decisions.

Christine explicitly says that by virtue of their age and hence cognitive developmental stage, adolescents are not expected to fully understand the impact of "bad behavior." They therefore they can be seen to be making uninformed decisions, and are forgiven for their transgressions. The transplant team recognizes that adults, on the other hand, are

expected to have a fully developed rational decision-making apparatus, and have been given full responsibility for their actions.

The transition to adulthood can be difficult for families. Post-transplant coordinator Carol put it thus: "When you transplant children, they have their mothers there. Their mothers hover and take care of them forever, and then there's a difficult time, adolescence, and maybe when they're trying to get out of the house, they have to try to let go." In well functioning families, parents begin to trust their children to make responsible health decisions—even if those health decisions may result in their death. This was illustrated in a long discussion with clinical social worker Rebecca, who described a patient with autism who was considering whether or not to be listed for a second transplant after her first failed:

> R: The mom is the legal guardian of note, though, but the mom feels very strongly that she believes her daughter is capable of making the decision and that she would honor whatever decision she makes. The mom acknowledged that would be really hard if she says I don't want a second transplant. So the mom already in her mind would want her daughter to have a transplant, and the patient knows that.

This patient wondered whether having a second transplant was "worth it," which is to say she wondered whether she would achieve an acceptable quality of life after the first transplant; her first transplant gave her an acceptable quality of life for about one year, and then experienced declining health for another eight years. Importantly, the patient's mother described the patient as adherent to medications and clinic follow-up and highly engaged with her caregivers and support systems. This likely improved the trusting relationship between mother and daughter.

Conflict among family members can occur when the transition to adulthood is "unsuccessful." Nurse and post-transplant coordinator Carol discussed a patient in remission from alcohol abuse disorder, who had a relapse approximately one year after receiving a liver transplant. In describing this case she noted the attitude of the patient's family:

> R: Everybody's sad and frustrated…we brought him in; we had an appointment with the social worker, with the patient; the family was there -- although he asked the family to leave. He's a grown man, but they tended to treat him like a child and get very angry…

Inability of the patient to adhere to the post-transplant treatment plan resulted in loss of trust among this family. A comparison of the above cases reveals the underlying pattern that those who demonstrate ability to adhere to treatment are labeled as normatively "good" patients and those who don't are "bad."

It also reveals an interesting assumption about patients who have substance abuse disorders or relapse. The relapsed patient described here is simultaneously an adult who is responsible for his relapse and a child who is not capable of making his own decisions. This may be a result of selectively adopting the negative components of both the cognitive and biological views of addiction, creating a conflicting view of responsibility. If one accepts a primarily cognitive view of addiction (i.e. a view that drinking is a choice, which—while no longer the standard of care among psychiatrists—may certainly exist among the general population), then one is committed to saying the patient is responsible for his relapse. If one accepts a biological view (that addiction is primarily caused by activation of reward pathways in the brain, and that impulse control becomes

weakened for such individuals), then the patient may be absolved of responsibility, for changes in brain states are outside of the patient's control.

3.6 Moral Community

When disagreement arises within the team about the right course of action for a particular patient, the team functions as a moral community to resolve the issue. A moral community is a group of individuals bound together for a common moral purpose that transcends personal interests and promotes the wellbeing of others (Volbrecht, 2002). In a healthcare context, the moral end is the wellbeing of both patients and caregivers (Storch, 2007). With the exception of Dr. Adams, all five of the other participants described deliberating upon and subsequently presenting decisions about complications as a team endeavor.

Several participants described the value of discussing difficult outcomes in a team setting. Carol, RN and post-transplant coordinator, recounted the approach the team took when evaluating the death of a young man who received an en-bloc liver, pancreas, and intestine transplant. In this case the team had a multidisciplinary conference to evaluate the patient's care and determine what, if anything, should have been done differently. Importantly, the tension between stewardship, efficient use of resources, and potential benefit to the patient entered into their deliberative process:

> R: …Hindsight's 20-20, so sometimes you identify things that, you know, in his case, maybe he was too frail at the time he got transplanted. Maybe we shouldn't have done it…I don't know how many millions of dollars were spent on that guy, and I know there are people in other parts of the world, and there are children in our own country, who don't get health care. That's an ethical dilemma for me…But I also see what transplant can be for people, and it can really give them a normal life. Some of them go on to have children, get married, contribute to society. So, again, to be that one…you

> can't predict with 100% accuracy all the time, so you just make the judgment as a team -- there's never one person that makes the decision -- and you go with it.

NP Christine described similar difficulties when discussing how the team handles giving second chances to young patients after a transplanted liver has failed secondary to immunosuppressant non-adherence:

> R: …This is something that our transplant selection group struggles with, because they are young. Someone who maybe made some poor decisions as a teenager, because they are struggling with separating from mom and really not able to make, I hate to say, adult decisions. Really, they are not mature enough yet to be able to understand what the decisions that they make right now as they are separating from mom and dad, how that effects long term versus someone who is adult should be able to understand immediate acts and long-term decisions…Believe me it's definitely something our group struggles with over and over again, because you are now taking the gift from somebody else that potentially could benefit and you are giving it to somebody else…are they going to make the right decisions again, or are they going to make poor decisions?

In both cases, the team is described as a moral community that deliberates ethical quandaries together, as well as a safe place to discuss morally blameworthy actions. In the first excerpt, the team struggles with whether they could have taken additional action to prevent the improper selection of a frail patient; underlying this is a sense of team responsibility for the patient's death. In the second excerpt, the team wonders whether they should allow a young person to be listed for a second transplant: does the patient's age allay his responsibility for losing the first transplant?

A third excerpt, from living donor social worker Susan illustrates the extent to which the team will act as a moral community which comes to consensus on morally suspect behavior when there is disagreement amongst the professionals. Susan discussed

the case of a young man who wished to donate part of his liver to his father, yet questions arose as to the patient's candidacy to donate due to a history of recreational drug use:

> R: …Really, it is so personal, honestly, what you bring to the table from your experiences, both professionally and personally. [The surgeon] shared with us how he was good friends with this anesthesiologist who started doing drugs. It caused him a whole world of problems professionally, lost his license. It was just this disaster. This surgeon was close friends with him. He was a really good guy, an excellent doctor, all these different things. I think he brings that experience to the table. There's certainly a notion that doing pot is a gateway drug for all kinds of other things, and that is true in some cases, but it's not uniformly true across the board. So I think not knowing…No one person—The surgeon is not expected to have all this chemical health knowledge to this great depth. That's why it's a team decision. That's why we consult other experts, but he brings that to the table when we're talking about people that have had chemical health history issues in the past or even are recreationally doing this drug or that drug.
>
> It really set him off with this other kid. He went on to donate to his dad…He has done a little bit of cocaine recreationally. He's a really bright, upper middle class, well-resourced, very social, well-educated guy and had done a little recreational cocaine. The surgeon was really freaking out about that, and I understand that. He's the one that's going to cut this kid open and dissect his liver and he wants to make certain that he's going to be OK, that it's going to be worth the risk. I get that. I do, too. I'm a licensed professional as well. I don't want that on me either, but there's a difference; this was in the past for him. He's not actively currently using.
>
> We just go through that. It's like well, what else do we need to know as a group to make this decision? Is there anything that would change our minds about this decision? Do we need to consult other professionals? Truly, so far my experience has been that things work pretty well and that there's been minimal conflict…

In the following quote, the use of the article "we" implies an understanding that once deliberation has taken place, the team is a single entity making recommendations for future care:

> R: Now they are not a transplant candidate or because of their infection or something like that. Then it's how far do we go? Do we keep pushing? Do we intubate them or does he really want this? How far do we go before we finally say, 'No. You'll never be a transplant candidate'?

Post-transplant coordinator Carol, RN, was more explicit when asked whether patients ever look to one team member as the ultimate decision-maker:

> R: No, because we never present it that way. It's always a team. We have a team selection conference, and it's the social workers, the dieticians, the pharmacists, the nurses, the doctors, so it's never a one-person decision.
>
> I: Has anybody ever expressed feeling responsible for being the deciding vote, being the person?
>
> R: No. That would be really arrogant…I think everybody realizes we're a part of the team. Everybody has a say. And we have to listen to each other. We see different things. I may know the family better than the surgeon knows the family. They know the medical part better than I know the medical part. The social worker knows the chemical dependency part probably better than I do. Everybody has their piece of information to bring to the table.

Carol seems to say that decisions are presented by the team not only for instrumental and moral reasons (i.e. agreeing upon the right course of action and communicating that in a united way to the patient), but also for the practical reason that no one person has enough expertise to make a complex decision about a transplant patient on their own.

Dr. Adams was a counterexample to the predominant sense that decisions are made as a team. He believes that it is his role to lead the team in making the ultimate decision and conceives of excessively democratic decision-making as chaos-inducing:

> R: There has to be one captain, there has to be one captain. The place I trained before, the University of [X], there was the surgeon who managed the ICU and the surgeon was the captain of the team that made all the decisions. The University of [Y] is like, what can I say, like a democracy and everybody has an opinion, but there it was like a dictatorship, the surgeon did the surgery and he gets to make the decision. The buck stops with the surgeon. Here, unfortunately, in The University it is not like that; in The University everybody has a say… the thing is you've got to have a captain. If you have a ship, if you have four or five…if you have all the inmates running the show then nothing is going to happen. You've got to have a captain. You can have a multidisciplinary team, but you've got to

> have a captain. If you don't have a captain, then there's no direction that the ship will go.

Importantly, Dr. Adams also said that he probably represents a negative case; that is, his beliefs on the authoritarian role of the surgeon likely does not reflect the beliefs of his colleagues. As a whole members of surgical teams view their work as collaborative, involving both real and hypothetical spaces in which ethical problems and responsibilities are deliberated and decided upon in consideration of the "best" outcome for a patient.

3.7 Relationship-Building, Empathy, and Trust

Participants frequently described fostering trust and using empathy to build a strong relationship between the patient and the transplantation team.

First, they impressed the importance of maintaining strong relationships with patients. Clinical social worker Stacy described her recurrent role as a source of support for a patient whom she had not cared for in several years, and in doing so emphasized that a strong relationship with her patients allows her to manage conflict between the patient and the team, as well as address behavioral complications. In one instance, the patient felt she was being ignored by the surgeon, who she would e-mail with a question but receive a reply from her post-transplant care coordinator. In this case, Stacy acted as a sounding board for the patient, helping her develop a strategy to address her concerns with the surgeon and care coordinator. In other cases, Stacy may receive a phone call from a patient who has had an alcoholic relapse or other behavioral complications. In these instances, Stacy said a strong relationship with a patient allows her to address the problem head-on, without having to worry about upsetting a patient for asking difficult questions. In a third scenario, Stacy may receive a phone call from a patient who she has

not managed in many years, yet because of their relationship history she finds it easy to pick up with that patient's care where they last left off.

Stacy summarized the utility of having a strong relationship with her patients in the following way:

> R: I think, you don't *have* to have a really good fit in order to care for people, and care for them, and take care of their medical needs and things. But I think when you are looking at populations of chronic illness, if there is a connection, I think from the practitioner's point of view, they would be more satisfied with their work. I think patients and families are going to feel more comfortable and more open to planning, and working, and collaborating, and adhering to their plan.

Trusting relationships are not required, but they improve team function, care delivery, and satisfaction for both patients and providers.

The variety of contexts in which team members recognized the utility of strong relationships with patients is summarized in Table 2. Note that post-transplant coordinator and nurse Carol is in a particularly unique position to observe the utility of fostering strong relationships, explaining why she is represented so often in the following table.

Table 2. Contexts in Which Trust is Instrumental

Provider	**Context**	**Representative Quote**
Stacy, Clinical Social Worker	Adolescent non-adherence	"…it isn't about statistics and all of those things. It's about giving people a longer life of which it is good quality. That is our goal. If we can together come up with those goals…to have somebody talk to you about what you want to do and how to get there, and how to take care of your health is going to be more apt to get you there."

Susan, Donor Coordinator	Supporting the parents of two patients	"In my role, I really can't do much. I'm not in there fixing it for [*the patient*]. It was lots and lots of emotional support, lots of just being there with the family, supporting them. It sounds all very fluffy, but I think it was really important, helping them just to persevere through that."
Carol, Post-Transplant Coordinator	Reconnecting with patients lost-to-follow-up	"…I don't know what Bill will do tomorrow, but I can call him and say, 'How are you doing?' and if he's not doing well...I don't know what Rachel's going to do. 'Do you have an appointment? Can I help you make an appointment with your mental health provider?'"
Carol, Post-Transplant Coordinator	Being available to a patient in need	" So he got his third transplant a year ago, he's working hard, he's in school -- he's disappeared. And he'll call me when he gets into trouble; I mean in terms of not feeling well…"
Carol, Post-Transplant Coordinator	Reconnecting with patients lost-to-follow-up	"He, too, disappeared on me for a while, but if you try to build a relationship with them, at some point they'll usually call you back."
Carol, Post-Transplant Coordinator	Reconnecting with patients lost-to-follow-up	"I lost touch with her for a while. I find her, she disappears. I find her, she disappears. I send her a letter, a month later she'll call me. Yesterday she profusely, 'Oh, I'm so sorry. I know. I've been bad. I'm going to call you, I promise. I really do have a phone now and you can use it, and I might even answer it.' I'm like, 'Rachel, I have to be in touch with you, because these medications have side effects that can be hard on other things."
Carol, Post-Transplant Coordinator	Fostering a relationship between the patient and the transplant team.	"…we're a special connection for patients, and I think that helps to give good care. They come in, the physicians are personable, they get dedicated sit-down one-to-one time with the family. We encourage families to have conversations about

		transplant issues, or give them direction on where to go for things that aren't directly transplant-related…I think they have a lot of times been stretched to the limit financially, emotionally, so just having that extra support I think encourages them and gives them strength to keep going. Because it can be really difficult."
Carol, Post-Transplant Coordinator	The instrumental value of a strong relationship	"if you take care of somebody for 20, 30 years, sometimes you have to teach them the same things you taught them 30 years ago, 30 years later. That's why it's important for us to have an ongoing relationship and check in with people. It really is a continuous process. And it's not just lab appointments, or appointments when they come to the physician. That's the role of the nurse coordinator."
Carol, Post-Transplant Coordinator	The instrumental value of a strong relationship	Even though they maybe come in once every six months or a year, or some people every three months, we have a lot of contact with them. They call us for a lot of things between visit times, for minor problems, whatever it may be. So we have a really, really close and ongoing relationship with the patients.
Carol, Post-Transplant Coordinator	A patient dies of suicide	"We develop really strong relationships with these patients. We try to remind them that we have resources for them, we're available to them; and you feel kind of defeated, but also, you understand."

Post-transplant coordinator Carol went on to summarize the moral value (as opposed to the instrumental value) of a close relationship with a patient:

> I: Can you think of another time when you felt like you had a close relationship with a patient?

> R: Oh, a million times. I have fostered relationships. I always feel like, as a nurse, if I lose the desire to have a connection, maybe a bit of a personal connection with people, then it's time for me to get out of nursing. As a nurse, I feel like you have to give a little bit of your heart to people. I know maybe not everybody feels that, but I do.

For Carol, fostering a strong relationship with a patient is not just useful in long-term follow-up, but is central to the practice of nursing.

Across participants, building a strong relationship with a patient depended on demonstrating trust and empathy. Empathy was shown to be useful in balancing the emotional tenor expressed by patients and their family members in several instances described by Rebecca, MSW; Susan, MSW; and Carol, RN. In Rebecca's story, the sister of a patient expressed anger at the situation when she and the patient were informed that the patient was too sick to be listed for a transplant:

> I: What did you say to her when she expressed that anger?
>
> R: Just reflecting that I understand why you're angry, I feel for you in this situation, this is a very difficult situation for us to be in as well as for you. This is your dad; he's not going to make it. She was very tearful. A lot of our patients get really frustrated about the allocation system …You had to have a high enough MELD score to get here, and now it is high, and now you can't transplant on him…So validating her feelings, because many of her thoughts and frustrations are not unfounded; it isn't always a fair system, and it is difficult.

Here, Rebecca demonstrates both emotional intelligence to identify the feelings the patient's sister was expressing, and reflective communication with an additional understanding of why the family member feels that way.

In navigating a visit with a donor who experienced muscle breakdown due to incorrect positioning on the operating table, and subsequent difficulty walking, donor coordinator Susan responded to the patient's tearfulness and frustration:

I: How do you approach that then?

R: Always initially my first approach is I apologize. I start out by saying 'I am really sorry that this has happened to you. This is not how it's supposed to go.' Usually, they're really tearful, which is completely understandable. I do a lot of empathizing, a lot of support. Then I start asking questions about identifying if they're having more serious depression issues or anxiety issues. If so, what might be appropriate mental health treatment? I start with empathy/support and move into an evaluation of where are they at from a mental health perspective, knowing that symptoms they might have right now, they could change and are completely understandable and normal. I normalize things a lot. 'Yeah, it's really normal to feel regretful about this. This is not supposed to happen.' He responded really well to that…[*rhabdoymolysis*] doesn't happen a lot, thank god. It's scary when it does and you're like, oh my god! We just talked about what kind of needs does he have at home. Is he getting support from his wife, from his family? How has that been going?

We talked through coping skills and strategies, all those things. All my years of working in mental health is hugely helpful in this, because when things do go wrong these are really good skills to have, not only assessment skills, but how do you support and empathize with people and figure out what might be helpful. How do you help teach them coping skills with their situation, such that it is?

Susan shows how demonstrations of empathy allow her to both connect to patients and formulate relevant clinical and psychosocial plans, again revealing the intrinsic and instrumental value of empathy between the transplant team and the patient.

While Rebecca and Susan represented the ability of social workers in this study to demonstrate and utilize empathy, post-transplant coordinator Carol again summarized the centrality of empathy to nursing practice. When describing the reaction the team had to the completed suicide of a patient who had recurrent liver cancer many years after receiving a liver transplant, she said:

As a nurse, you're very in touch with people's feelings, and empathize, and try to put yourself into their place, where they've already troubled their family with all that it takes to get a transplant, the cost of the transplant --

> and then they see another big cancer diagnosis and more treatment down the line, and you can try to understand that they just couldn't do it any more.

Implied in the phrasing "as a nurse…" Carol again states that empathy is an underlying value in the practice of nursing.

Trust

Trust is a multifaceted concept. It variously appeared as explicit conversations about creating trust with the patient, which Dr. Adams explored, or as illustrations of various components of trust, which other team members described.

Dr. Adams' method of establishing a trusting relationship with patients relied entirely on setting medical goals and delivering on the promise to meet those goals. Dr. Adams also said he does not discuss specific outcomes with patients, just that he can provide a "successful" transplant. Importantly, Dr. Adams believed that establishing trust was independent of demonstrating deep empathy. In fact, the only other important factors are to exude confidence and demonstrate a history of good medical outcomes:

> R: Patients go by the level of confidence you exude. If you are a willy-nilly shaky kind of a guy they don't trust you. A lot of times it's outcome dependent, too, you know you promise them, if you can deliver what you promise, then they will usually trust you. That is why I never promise something I can't deliver, because that's when your credibility gets lost. You should always under-promise and over-deliver.

He stated that establishing credibility means setting expectations that the surgeon can easily meet, and not over-promising outcomes to the patient—even if that upsets the patient. In Dr. Adams' view, under-commitment to surgical outcomes is acceptable to 98% of patients. For the remaining two percent, "I tell them the way it is and if they don't like it, they don't like it. I tell them that I don't promise

something I can't deliver, and if they are not happy with me then they find another surgeon."

Even in instances of conflict, Dr. Adams sees demonstrations of competence as the most effective way of showing the patient he is trustworthy. In one case, Dr. Adams took on a patient who did not like his personality:

> R: He said he didn't like my talking to him, etc., etc., but then he said 'you're a competent surgeon so I want to go with you…he said I was the best surgeon he could find so he went with me. Yes, there are lots of patients who actually don't like me, but they like my outcomes, so that is why they come to me.

Importantly, Dr. Adams feels he is unique among surgeons for his blunt honesty with patients and their families. He told me that "most surgeons will tell you what you want to hear," referring again to his strategy of under-promising outcomes. Interestingly, Dr. Adams has somewhat magical thinking with regard to gain patients' trust. In the above selections he described leveraging his history of positive outcomes to gain patients' trust prior to the transplant. However, for those who choose to have him as a surgeon despite their dislike for him, trust is gained after the fact:

> R: …They come here and they hate me, then I do their transplant, suddenly they have a magical recovery and then they start loving me. That is usually what happens…

Dr. Adams holds honesty in particularly high regard. When asked about a time when he lost a patient's trust, Dr. Adams identified perceived dishonesty is the source of that conflict. He told the story of a physician who received a liver transplant and returned to the hospital one month later with central pontine myelinolysis, a type of brainstem damage which may result in paralysis, coma, or even death. This patient was admitted to the intensive care unit, and his family was given a grave prognosis by the intensive care

team. Dr. Adams was not convinced, however, and told the family that based on his 15 years of experience as a liver transplant surgeon, the patient would recover and live a normal life. Dr. Adams was "fired" by the patient's family, (i.e. told he was not allowed to care for the patient anymore) recalling, "The family said 'we are hearing two stories from you and from the intensivists, and we think you are just fibbing, and you're fired." Dr. Adams felt that in this case, the ICU team established trust with the patients family by incorrectly claiming that the moral course of action was to allow the patient to die. He again referenced the family being told "what they wanted to hear":

> R: They wanted to hear that he is sick enough and he shouldn't suffer. The ICU physician told them what they wanted to hear. I told them what they didn't want to hear, which was to persist, and to let him go through a little bit of suffering so that he can eventually get better...

Dr. Adams closed his interview with a summary of his views on creating trust:

> R: I think the most important story…is to remember that as a physician you've got to be competent and you've got to be honest. That's the only story I have. Everything else is fluff. And never cover up your incompetence by trying to be personable. Don't mask the incompetence by using interpersonal skills.

While Dr. Adams was clear in his explicit conversation about what he believed to be components of trust-building, readers should note that the underlying structure of his stories conform to general methods of establishing "swift trust," as described in the introduction above. In these stories, Dr. Adams encounters vulnerable patients, and both communicates his good will towards them while setting expectations for a good outcome. The focus communicating how frequently he achieves a positive outcome may be an attempt to demonstrate instances of trustworthiness for the new patient.

Although Dr. Adams believed interpersonal skills to be "fluff" and unimportant to establishing trust, various members of the transplant team described the importance of communication to maintaining their relationships with patients. Rebecca, MSW described the importance of communication over the long-term when discussing the reaction of the mother of a patient with a difficult months-long post-operative course complicated by cancer. Understandably worried, this mother's hope was maintained by physicians who frequently updated her about the patient's medical condition, and often told her that the patient's acute medical problems had clearly defined, reasonable treatments to reverse them. This patient also followed with a particular hepatologist for many years, and so trust between the patient and this physician had already been established. The patient's mother therefore "trusted that we had his best interests at heart."

Rebecca also said that she shared hope for the patient's recovery with the patient's mother. In part, this was because in the team's medical opinion, treating the patient's illness was not a futile endeavor. Additionally, it is a part of practice to normalize medical treatment in a complicated post-operative course:

> R: We were doing things that were appropriate and that followed the course of a complicated recovery. I think a lot of times we're normalizing that some patients do have complicated recoveries and it can look like this. Also reminding them, though, if we reach a point where medical treatment is not going to help somebody, it's our duty to tell them that.

Rebecca's story demonstrates the late phase of a trusting relationship and highlights an important aspect of trust-building: fostered good-will. The hepatologist in this story had known the patient for several years and had cared for him through his transplant. Treatment recommendations until that point had resulted in the patient's continued stability, which convinced the patient and his mother that the physicians were acting with

fiduciary interest in him. Rebecca continued to communicate that good-will with the patient's mother, maintaining her confidence through her son's rocky post-operative course.

Dr. Adams also suggested that patients ultimately seek medical care because they desire recovery from illness, and that it is a part of his practice to normalize expectations for a positive outcome in a complicated post-operative course. When asked how patients create expectations for transplant, he responded, "Patients don't; patients just want to come here and they want to get better, that's it. Their expectation is that they will get better and get good care." Maintaining these expectations for positive outcomes was an explicit part of the work performed by social workers and nurses on the team. Clinical social worker Stacy discussed maintaining positive expectations as a duty she performs when patients experience rejection:

> R: …Some patients get rejection through just pure happenstance. They've done everything they need to, and it happens. They just happen to have a liver that needs higher immunosuppression, needs something, they have a virus or something else that put them over the edge…As a social worker, my biggest intervention is letting them know that in most cases, especially acute rejection, the physicians can treat it. It's not necessarily anything they did or didn't do.

Similarly, Christine, NP discussed "staying positive" on behalf of a frustrated patient with several complications prior to transplant due to liver ischemia:

> R: … He was frustrated heavily, because of waiting and waiting and waiting and things outside of his control, just trying to stay positive. It was a long time before he got his liver transplant. He got really sick.
>
> I: You said just trying to stay positive. Was that part of your role in his care?
>
> R: I think so. It was coordination of recurrent ERCPs, then he was having pain along with it and itching, so it was managing all his extra hepatic symptoms that he was having, that was my role. Of course, trying to

> communicate with our group periodically saying, 'is he infected? Is he up to date with all his screening? Are all those things taken care of? If an offer does come available, is he ready?'

Here, both Stacy and Christine state that when patients are demoralized prior-to or following their transplantation due to a medical complication, it is their role to communicate that the medical providers on the team can fix the problem and deliver on that communication, which establishes an expectation for good outcomes.

In comparison to the above, Rebecca illustrated how trust can be lost when patients or their family members do not perceive the team to have good-will towards them. In one case, the husband of a sick patient who was transplanted after many-months wait was frustrated after several delays in care. Here, Rebecca recalled setting an expectation that the patient would remain hospitalized for up to six months post-transplant due to the severity of their illness. The patient's husband became frustrated two months into the treatment course in light of many delays completing procedures, being away from home, or minor complications with feeding tubes. He would also raise complaints to the team about major treatment decisions, which the team found difficult to stomach. I asked Rebecca about the point at which she thought the patient's husband lost trust in the team:

> R: I feel like he even lost a fair amount of trust even before the transplant, because he had a lot of judgments about why she wasn't re-listed sooner than she was. Again, she was very sick. It was kind of marginal—should we proceed with a transplant or not? From the team's perspective, it was tough.

Perception of good-will depends on convincing the patient or their family that the team has the patient's best interests at heart. In the case of chronic life-threatening illness, it is reasonable to interpret this patient's husband as expecting to receive care as soon as

possible to avert her death. Each delay in care was perceived as not fulfilling that fiduciary interest, and therefore a perceived lack of good will.

Similarly, if the team cannot maintain positive expectations about the outcome of the case (generally expected to be medical improvement), then trust may also be lost. Clinical social worker Rebecca also described this problem in a general discussion about meeting expectations:

> R: Some of our patients are very, very sick going into the surgery and others are very sick by definition. [*That is,*] they have an indication for transplant, but they're physically actually doing very well. So that type of a patient comes in for a transplant, they may have worked the day before, and they're doing quite well. They come in for a transplant and their course is more complicated, whether it's medications or the actual complications, or just their course is longer than anyone anticipated. Or maybe they're home in seven days but then they're re-hospitalized. Just their overall recovery is harder than they thought, because in their head they were going to be off work four or six weeks. It's not necessarily that we tell them that; we usually say more than that—quite a bit more than that—even for people who are doing quite well. But in their mind, they had an expectation and it didn't go quite the way they had planned, and maybe they still are dealing with consequences of the transplant, so I think sometimes we don't meet their expectations. Whether or not those are realistic expectations, we're not meeting them, because something isn't going as well as it could and that's hard for people. I think they just don't always have that envisioned that it wouldn't go perfect, or it wouldn't go exactly as they had planned.

When the team is not able to meet the patient's expectations, it establishes a precedent of negative outcomes, subverting the tenant that maintenance of expectations for positive outcomes is essential to maintaining trust.

Importantly, trust is bi-directional. Several members of the transplant team used the coded language of "having faith" to communicate that in addition to attempting to gain the trust of their patients, team members must trust that patients will uphold their end of the treatment relationship. Post-transplant coordinator Carol discussed her hope

for a positive outcome in the case of a young man with mental illness who needed a liver transplant:

> R:…At the time he was transplanted, I think he was so sick...They get so sick afterwards, too, that ... Again, sometimes it's a leap of faith.
>
> I: What are you faithful of?
>
> R: Hoping that once they feel better, they'll be able to be compliant; or have somebody on the outside calling them and saying, 'Okay, you're not doing well. You need to get in to see your mental health provider.' A leap of faith that there will be somebody to see them. That's a hard one.

Donor coordinator Susan also used the language of faith when relating the story of a young man who wanted to directly donate a portion of his liver to another member of his church congregation. The team struggled with whether to approve the donation because the patient had a history of mental illness and did not know the recipient very well, whereas patients are usually only accepted as donors if there is a strong tie between patient and recipient:

> We took a little bit of a leap for us on this issue and, fortunately, things turned out very well for all involved. His recovery was completely textbook and uneventful. He was out of the hospital in five days. Usually a donor hospital stay is five to seven days for liver donation. No complications, mental health really stable; he did great. That might not have been the case. He was happy to do it. He had no regrets, no remorse.

In both instances, the story-tellers fulfill the general qualities of trust-holding. They are each vulnerable because the team has invested emotionally and physically when providing a transplantable liver. They both maintain expectations for a positive outcome after the patient has received a transplant and hope that the patient has the goodwill to fulfill their treatment responsibilities.

Chapter 4. Discussion

This study had two main aims. The first was to document what members of liver transplant teams perceive as causes of disagreement among and between the team and patients. The second was to interpret the moral understandings transplantation teams hold within the team-patient-family dynamic. In meeting these aims, this study also explored the ways that conflict is managed. Analysis of the interviews obtained revealed three main themes. The first theme was "Sources of disagreement extend beyond treatment non-adherence." This theme describes the varied stories of disagreement among and between transplant teams and patients which heretofore have not been documented in the literature. The second theme was "The transplantation team acts as a moral community," describing the approach that transplantation teams take to evaluating and deciding upon ethical questions. The final theme was "Transplantation teams manage conflict by generating high levels of empathy and trust," which captures the approach that transplant teams take to disagreement and accounts for low levels of intractable disagreement encountered in this study. Each theme will be addressed in turn.

4.1 Theme One: Sources of Disagreement Extend Beyond Treatment Non-Adherence

The extant literature on treatment disagreement in the context of liver transplantation largely focuses on non-adherence to medication regimens and clinic attendance. An assessment of all literature on these topics was beyond the scope of this project, as studies were too numerous to efficiently review. The first literature review in

this study therefore used “treatment refusal” as a database search term, as opposed to “non-adherence” or “non-compliance.” The latter two terms tended to produce studies evaluating rates of medication adherence and clinic attendance, whereas in using the former term, an attempt was made to review transplantation literature that assessed the reasons underlying deviation from the treatment plan. However, “treatment refusal” still generally resulted in reports concerning rates of medication and clinic adherence (see Laederach-Hofmann & Bunzel, 2000 for a representative example).

Other reports were limited in scope: just three concerned alcoholic relapse (one of which was anecdotal and the other two of which were epidemiological), one was a superior court decision regarding blood-transfusion refusal for religious reasons, another was a case series also regarding religious refusal, one was a news report about stopping treatment after transplantation failure, and the last was a report of a patient with borderline personality disorder. The literature lacks comprehensive accounts of why patients and providers disagree about treatment-decisions in the transplantation context, though the reviewed studies did hint at major reasons why disagreement does occur.

This study generated storied accounts of disagreement both among providers and between providers and patients. Disagreement could be broadly described as behaviorally rooted, that is patient action, as opposed to pure medical complication, created disagreement. These disagreements were related to treatment non-adherence, alcohol abuse, and mental health issues This study reflects the above literature but adds a deep description of known problems, revealing unexpected ways in which conflicts play out. Physiological complications were normalized as an expected component of post-

transplant care and were managed accordingly; they did not represent sources of major disagreement with patients or families.

First, treatment non-adherence was commonly discussed. Interestingly, however, it was frequently perceived in the context of adolescent decision-making, even among some adult patients. Participants told stories of young patients who received their first transplant in childhood. The stories adhered to a pattern of transplantation, followed by a period of normalcy in which the patient received regular follow-up for their transplant, then disruption caused by the patient's realization that they had obligations different from their peers, and finally non-adherence in which the adolescent desired to "be normal" or live a "normal" life. These patients were described as deserving of a second chance at transplantation because "kids make stupid decisions," i.e. they are not fully autonomous agents who understand the ramifications of non-adherence should liver damage occur. Curiously, some adults were also labeled as adolescent, however they did not receive absolution for their behavior. The most notable example of this was a patient with alcohol use disorder who was described as being "treated like a child" by his family.

That patients with alcohol use disorder may experience relapses that interfere with their post-operative care is not surprising. Here, I have documented the need to confront patients experiencing relapse and the difficulty of navigating a conversation fraught with embarrassment, evasion, and feelings of blame. However, this study also documented that alcohol use can cause conflict with family members, within the team, and with other hospital personnel that also enters into the scope of team members' concerns. Particular findings here included misunderstandings with family members over meeting initial sobriety as a sufficient requirement for transplantation and tensions which develop

between the transplant team and other hospital teams following readmission of a patient during relapse.

Participants worried that transplanting patients with alcohol abuse disorder may lead to violations in their commitment to organ stewardship, and therefore the team may disagree with one another as to whether patients who relapse and experience liver failure should be re-transplanted. The root of this tension was an expectation of joint responsibility for maintenance of sobriety. On one hand, team members recognized that they had a responsibility to provide patients with resources to achieve and maintain sobriety. On the other hand, they believed that patients are ultimately responsible for choosing sobriety and, at least in some causal sense, for relapse. Transplant teams therefore debate whether patients who relapse and have recurrent liver failure should receive another transplant. This suggests they at least consider transplantation for alcoholic liver failure a potentially unjust or inefficient allocation of resources, which fits into general theory about liver stewardship (Veatch & Ross, 2012). To my knowledge, this will be the first time such an attitude has been reported among practicing teams.

Finally, mental illness was frequently disruptive to follow-up care. Patients with mental illnesses were often lost to follow-up due to decompensations, which is not an unexpected finding. As in the instance of alcoholic relapse, respondents also assigned ultimate responsibility for mental health maintenance to patients. Again, they recognized that the transplantation team must provide patients with the opportunity to maintain their mental health, but there are limitations on the availability of mental health resources, and patients cannot be forced to maintain their mental health.

The overall picture demonstrated dual senses of responsibility for behavioral causes of disagreement. This conformed to the two approaches one may take to responsible organ stewardship described by Veatch and Ross (2012). Alcohol abuse, mental illness, and propensity for non-adherence were not absolute contraindications to re-transplantation. In fact, in some circumstances, such as adolescent non-adherence, patients were absolved of responsibility for organ loss. This reflects the egalitarian approach of providing equal opportunity to organ transplantation to any patient regardless of their underlying illness. At the same time, organ loss caused participants to question whether patients deserved transplantation explicitly because it may not be "worth it" to provide a second chance. This reflects the efficiency approach, which focuses on maximal effective use of an available organ, necessarily accounting for underlying cause of organ failure and attempting to predict whether transplant failure will occur.

4.2 Theme Two: The Transplantation Team Acts as a Moral Community

This study is the first to consider the function of transplantation teams as moral communities. A moral community is a group of individuals bound together for a common moral purpose that transcends personal interests and promotes the wellbeing of others (Volbrecht, 2002). In a healthcare context, the moral end is the wellbeing of both patients and caregivers (Storch, 2007). Liaschenko and Peter (2016) have recently suggested that moral communities are both literal and figurative spaces where participants have moral communication, discuss their identities as moral agents, and understand mutual

responsibilities, values, and beliefs. The participants in this study described their process of evaluating disagreements according to these definitions.

The first action of a transplantation team is to decide on the listing of transplantation candidates. Although the decision is purportedly medical in nature only, with UNOS policy later deciding on priority of transplant candidates on the list, Veatch & Ross (2012) suggest that it is impossible to entirely divorce social worth judgments from the decision to list a candidate. The selection committee therefore represents a physical space in which participants decide who should and should not be listed. The deliberative process was described by participants as open and egalitarian. All participants may bring their concerns about the rightness of transplanting a particular patient to the literal and figurative table. All participants then come together to decide whether those concerns are well-founded. An example of one such case was that of the physician who did not want to allow a patient with a history of substance abuse to make a live donation to his father. Other members of the transplant team checked the physician's judgment as unreasonable, and the patient was ultimately allowed to donate.

When disagreement arises with patients and family members, the transplantation team also communicates decisions using group-oriented language. Decisions not to re-transplant, for example, are always presented as a group decision, giving force to the decision as legitimate. However, group-oriented language is not only used to communicate refusal to re-transplant. When patients face multiple kinds of complications, team members use "we" language to begin planning next steps (i.e. "What are *we* going to do next?"). Such an approach communicates inclusion of the patient into

the moral community. The patient then shares responsibility for addressing complications that arise.

Whether the entire group maintains this group perspective is an open question. This study had only one transplant surgeon participate, and that individual viewed himself as an authority figure opposed to democratic decision-making processes. He did note, however, that his viewpoint was likely in the minority, and that most physicians would endorse a democratic consensus-making process. Regardless of the participating surgeon's expressed views, other members of the transplantation team described physicians as having equal weight in deciding moral problems. Participants recognized that each member of the team brings specific technical and emotional skills, moral identities, and a unique experiential perspective, to the table, all of which come together to decide on multifaceted moral problems.

4.3 Theme Three: Transplantation Teams Manage Conflict by Generating High Levels of Empathy and Trust

There is an abundance of literature concerning the ways nurses, social workers, and internists relate to patients. This literature suggests that providers maintain relationships with their patients or clients by demonstrating empathy and fostering trust. When clinical relationships are strong, patients are more likely to adhere to, be satisfied with, and take ownership over their treatment plans. However, research on general surgeons, orthopedic surgeons, and obstetrician/gynecologists suggests that these providers do not foster empathy to as great a degree as the aforementioned providers. They do show high levels of emotional intelligence, which is the ability to perceive,

integrate, and regulate the emotions in oneself and others (Weng et. al., 2008). Emotional intelligence may be helpful for establishing trust and improving patient satisfaction, but it is not clear that it maintains relationships in the long term.

Transplantation teams clearly maintain successful long-term relationships with their patients. These patients are unique among surgical patients because they are chronically immunosuppressed and have utilized scarce resources, much like patients in non-surgical contexts. The literature lacks accounts of how transplantation teams function to maintain such relationships with patients and each other. The non-transplantation literature on trust, empathy, and relationship-building suggests that these teams may have improved outcomes if they are able to exhibit these traits, avoiding loss of a viable organ. While the team in this study identified several sources of conflict, they also described managing these conflicts to the best of their ability. They therefore represent a group whose techniques would fill a gap in the literature.

First, it is important to note that the providers in this study reported that non-behavioral complications, including acute rejection, infection, primary non-function, cancer, and others should be treated. They did not perceive these as sources of disagreement with patients because they believed they normalized treatment of medical complications as a routine part of post-transplant care. Complications that caused disagreement were behavioral in nature. Relevant behaviors included those which occur in the context of human interaction: substance abuse, mental health decompensation, and general non-adherence to medication regimens or clinic attendance. The context of human interaction is important because a patient's social context is potentially modifiable by care providers who exist within that interactive space.

Indeed, in this study, all providers emphasized the importance of establishing trust with their patients. Dr. Adams described trust in the swift sense described by Lazzara et. al. (2016). This sort of trust is specific to temporary systems such as the clearly defined initial transplantation period. It is important to note that the "clearly defined" initial transplantation period may last many months, which is substantially longer than other conditions for which a surgeon may be consulted. For example, a patient with chronic gallstones may meet their surgeon and schedule a gallbladder removal at their initial visit. The contexts are similar, however, in that they share a discrete goal: removing that which is causing illness—and in the instance of transplantation, replacing it with a life-saving organ. As Dr. Adams said, establishing trust for this purpose may be a matter of demonstrating to patients that a successful initial surgical outcome can be achieved, and that the surgeon does have the interests of the patient (presumably continued life) at heart.

Past the initial transplant, the patient's care is managed in much the same way as any other medical patient. Patients are expected to periodically check in with the provider, bring to the team's attention any concerning symptoms, submit to regular laboratory screening tests, and take prescribed medications. This long-term relationship is maintained by the team as a whole, and responsibilities are divided by specialist. In over-simplified terms, surgeons and nurse practitioners address medical or surgical complications, social workers address inadequate support, and care coordinators maintain overarching connections with the patient. The most senior members (longest term) of the transplant team described an ability to reconnect with patients after many years without contact, or with those who were periodically lost to follow-up. These individuals served

as important anchors for unstable care. For several patients with mental health decompensations leading to inconsistent contact, post-transplant coordinator Carol described being able to cold-call the patient in order to check-up on them, later addressing any concerning findings.

Trusting relationships allowed many team members to confront both behavioral complications and interprofessional disagreements without concern for damaging the relationship. As described above (Bell & Duffy, 2009), members of trusting relationships are vulnerable with one another in light of goodwill that each shows for the other and faith of a positive outcome. For behavioral complications, particularly alcoholic relapse, trusting relationships allowed participants to directly confront behavior both parties understood to be "bad." Additionally, when participants demonstrated empathy, they adopted good-will stances towards their patients. This was seen in the case of completed suicide, and was directly noted by both social workers and nurses as key tasks to their position.

Finally, trusting and empathetic relationships allowed providers to resolve disagreements with one another. It is not sufficient for the moral community described above to be designated as a space to discuss moral identities and understandings. Participants must trust one another in order to participate; they must make themselves vulnerable to the charge of moral incorrectness as they wrestle with moral questions. Although participants in this study did not explicitly state they trusted one another in these settings, they did use coded language: "everyone brings something different to the table" or in their discussions of insecurities that members discussed with one another.

This study suggests that much of the emotional work to maintain the team-patient relationship is done by non-physician providers. Although only one physician from the examined team chose to participate, that surgeon was clear in his belief that "interpersonal skills are fluff," meaning the maintenance of a deep relationship with his patients was not his duty. By comparison, social workers and nurses fulfilling multiple roles on the team (clinical and coordinating) viewed empathetic communication as central to their roles. They described successful navigation of disagreements centered on patient behavior by accessing the trusting relationship they had with patients to negotiate an acceptable resolution.

Chapter 5. Conclusion

This study's two main purposes were to assess what liver transplant teams deem to be salient conflicts in their practice, as well as the moral understandings underlying these conflicts. In assessing this question, I examined current literature on transplant patient non-adherence, basic problems of organ stewardship and allocation, and some aspects of the patient provider relationship. The literature review suggested that the current literature has only considered non-adherence *per se* and not the underlying reasons *why* patients do not adhere, raising the first question this study sought to answer: what do liver transplant providers perceive to be conflicts regarding the treatment of complications? The literature reviews also suggested that transplant ethics has generally focused on problems of organ stewardship and allocation. While these are worthwhile questions for the field of transplantation surgery as a whole, they have limited value in understanding the ways transplant providers conceive of the morality of transplant in context. This therefore raised the second question of this study, regarding what moral considerations enter decision-making at the clinical level. Finally, consideration of surgical, medical, nursing, and social work literature showed that trusting and empathetic relationships were likely to lead to improved patient outcomes. Yet surgeons demonstrate less empathy in general than other providers. This raised the final question addressed: if surgeons demonstrate lower levels of empathy than their colleagues, but transplantation teams are generally able to manage conflict, what is unique to these teams that maintains the patient-provider relationship?

In answering the first question, this narrative study generated storied descriptions of conflicts that liver transplantation teams face within and among the team, patients, and families. This transplant team viewed complications with a behavioral component to be sources of disagreement, while medical complications were not. This finding is important because it adds depth to the current literature. Many studies exist evaluating medication non-adherence and clinic absenteeism, some assess alcoholic relapse, and few assess mental health. None, to my knowledge, assess these together.

This study answered the second question, regarding underlying moral understandings, by revealing multiple moral notions. Most notably, participants held the wellbeing of patients to be their greatest moral commitment, followed by organ stewardship. This is both expected and possibly concerning, because although it reflects the greatest body of transplantation ethics literature, it also brings into question whether considerations of responsible organ use (and therefore social worth judgments) can be divorced from the decision to list patients for transplant purely on medical grounds. Whether the two should be divorced is beyond the scope of this study, but scholars cited in this work have suggested this should be this case. Second, this study revealed that providers distribute responsibility for organ longevity amongst themselves and patients; in particular, those who had "behavioral" reasons for organ loss were held responsible and whether they deserved a second organ was questioned, while those who had a purely "medical" cause for complication or were an adolescent were absolved of that responsibility. Finally, this study is the first to describe transplantation teams as moral communities. They are a discrete group of individuals bound together for the moral

purposes of transplant patient wellbeing and organ stewardship, who examine their moral identities and responsibilities with one another in multiple contexts.

The final question, how transplantation teams are able to maintain relationships with their patients over the long-term when a prominent member—the surgeon—is less likely to exhibit deep empathetic relating than his or her colleagues, was answered by revealing the emotional work that other members of the team perform. Emotional work has long been recognized as the work of nurses. Both nurses and social workers hold empathy to be a virtue and they develop trusting relationships with their patients and clients. This study fit the existing literature in that regard. Nurses and social workers, in their varied roles, were important to maintaining patient engagement with the transplantation team during long-term follow-up. However, the study also revealed the extent to which transplantation teams utilize trust with one another to resolve conflict.

5.1 Study Limitations

The data was sufficient to generate a versimilitudinous picture of the conflicts surrounding liver transplantation, however the data could be most enhanced by greater participation, specifically with regards to physicians. Their perspective was represented in this study by one transplant surgeon who chose to participate, Dr. Adams, despite aggressive recruiting of this group. I am unable to say why physicians did not participate in this study. During recruitment, the time pressures of a transplant surgeon's schedule was frequently cited as a reason for declining to participate. It is also possible that mistrust of the researcher, or discomfort with the topic, influenced physicians' decisions not to participate. Given the finding that "behavioral" complications were a source of

disagreement, it would also be helpful to have the perspective of any mental health professionals who are considered a part of the team.

5.2 Future directions

The aim of a narrative study is never to achieve universal applicability. This study is limited by the fact that narratives exist in context. Whether this study is useful will therefore depend on the degree to which a particular transplantation team reflects the experience of the one documented here. Future work could address this problem by utilizing quantitative methods to assess the prevalence of this study's themes among other transplantation teams, perhaps through survey data. Future studies could also examine the relationship of both behavioral and non-behavioral complications to non-adherence, as well as whether transplantation teams in other locations perceive the same sources of disagreement as this team did. Examining patient experiences will also be key to understanding conflict within the complex team-patinet-family dynamic. Finally, future work should examine the function of trust in the transplant team setting. Narrative, phenomenological, or ethnographic methods would all be well-suited to this task.

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